COMMUNITY RESPONSES TO HIV/AIDS IN SOUTH AFRICA

FINDINGS FROM A MULTI-COMMUNITY SURVEY

Developed by

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Photographs courtesy of Kevin Kelly.

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Acronyms

ART	Antiretroviral Therapy
ASO	AIDS Service Organisation
CBHW	Community-Based Health Worker
CBO	Community-Based Organisation
CSO	Civil Society Organisation
DOH	Department of Health
DOTS	Directly Observed Treatment Short-Course
DSD	Department of Social Development
FBO	Faith-Based Organisation
HCW	Health Care Workers
IDP	Integrated Development Plan
IEC	Information, Education, Communication
IGR	Inter-Governmental Relations
LAC	Local AIDS Council
M&E	Monitoring and Evaluation
NAPWA	National Association of People Living with HIV/AIDS
NGO	Non-Governmental Organisation
NPO	Non-Profit Organisation
OD	Organisational Development
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children
PEP	Post-Exposure Prophylaxis
PWA	Person with HIV/AIDS
PHC	Primary Health Care
PMTCT	Prevention of Mother-to-Child Transmission
RDP	Reconstruction and Development Programme
STI	Sexually Transmitted Infection
TASO	The AIDS Support Organisation
TB	Tuberculosis
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary Counselling and Testing

Executive Summary

Background

This report presents findings from an audit of local-level responses to HIV/AIDS in three South African communities. Although widespread, such responses have often been overlooked and marginalised in favour of emphasis on large-scale centralised approaches to HIV/AIDS prevention, care and treatment. This study sought to explore the nature of local-level responses, the major actors involved with AIDS response at community level, the types of services being provided (and by whom), and the challenges being faced by local groups involved in AIDS response. It was also motivated by an interest in the applicability of notions of social capital – the capacity for heterogeneous groups within communities to act collectively to address shared challenges – to various dimensions of the HIV/AIDS epidemic.

The study was conducted in three communities: Vosloorus, a large urban township on Johannesburg's East Rand; Obanjeni, a rural area in KwaZulu-Natal; and Grahamstown, a medium-sized town in the Eastern Cape. The study identified and gathered information on the various types of formally organised AIDS activities happening at community level through a questionnaire administered by field workers. The questionnaire collected data on the organisation itself (type, years in operation, staff, volunteers, financial management etc.), the areas of HIV/AIDS activity in which it is engaged, the types of services provided, and successes and challenges encountered in AIDS response work. Additional in-depth interviews were conducted with selected key informants to better understand issues of co-ordination and integration of AIDS-related activities within participating communities.

A total of 179 organisations that identify themselves as having HIV/AIDS initiatives or activities participated in the survey. These include government institutions, civil society groups (community-based organisations and non-governmental organisations), faith-based organisations, schools, private businesses and medical practitioners. Some of the organisations are AIDS-specific in their orientation – that is, HIV/AIDS is their primary focus and mandate – while others have incorporated HIV/AIDS-related activities into their core work. The survey did not attempt to identify the many informal groupings, such as neighbourhood associations and care networks, which are also active in AIDS response.

Given the different sizes of the respective communities and different degrees of social mobilisation around AIDS, the number of organisations involved varied across communities. In Vosloorus 104 organisations involved with AIDS response were identified, in Grahamstown there were 67, and in Obanjeni there were eight.

This focus of this report is on the activities of the government institutions, civil society organisations, and faith-based organisations identified in the survey (n=88). It investigates the survey findings related to dynamics and patterns of activity among the community-level organisations and considers them in relation to the more centralised, 'official' public sector activities available through government institutions.

Main Findings

Community actors

A broad spectrum of organisations, groups and entities are involved in AIDS response at community level. Of the 179 organisations surveyed, 43 are civil society organisations (CSOs), 29 are government institutions or departments, and 16 are faith-based organisations (FBOs).

Approximately half of the organisations in the survey have become involved in AIDS response within the past five years. CSO involvement in AIDS response has grown by 61% since 2000, while the number of FBOs involved in HIV/AIDS-related work has nearly tripled (275% increase).

The majority of organisations report working with 'all ages,' while among those who single out particular age groups, the 13-19 age band receives the greatest emphasis.

Prevention activity is undertaken by the greatest proportion of organisations overall, followed by care and support, training, legal assistance and treatment. Government institutions dominate the provision of treatment, while CSOs and FBOs are more active in care and support activities.

Prevention

Prevention-related activities, defined broadly to include both educational/awareness activities and specialised interventions (e.g. voluntary counselling and testing (VCT), prevention of mother-to-child transmission (PMTCT)), are extremely common among AIDS response organisations. Eighty-eight percent of CSOs, 88% of FBOs, and 97% of government institutions report some form of prevention activity.

The most popular approaches to prevention, reported by more than three-quarters of organisations, are the promotion of condom use, abstinence, sexual behaviour change, and life skills. More specialised services, such as post-exposure prophylaxis (PEP) and prevention of mother-to-child transmission (PMTCT), are provided by a smaller proportion of organisations, which tend to be government-linked.

Approximately half (49%) of the organisations offering VCT services in the three sites are governmental, while another 45% are CSOs and 6% are FBOs. VCT procedures and practices are not uniform. For example, there are differences in testing methods, the availability of private space for VCT sessions varies, there are variations in the type of counsellors used, and support groups and referral networks are not uniformly integrated with VCT services.

Condom distribution is a common activity among some types of organisations, but uncommon among others. Eighty-two percent of government institutions and 55% of CSOs report distributing condoms, compared to only 14% of FBOs. Of those organisations distributing condoms, all provide male condoms, while less than a third distribute female condoms.

HIV-positive individuals are used as educators by 64% of government institutions, 53% of CSOs and 36% of FBOs. Approximately half (51%) of these organisations pay HIV-positive educators for their contributions.

Care and support

Seventy percent of CSOs are involved in providing care and support services to people with HIV/AIDS (PWAs). This compares to 55% of government agencies and 44% of FBOs.

The care and support services that are most commonly provided by respondent organisations are counselling, emotional care, support for PWAs, promoting community care, support groups, and support to families and caregivers. A smaller, but still sizeable proportion of organisations provide more specialised care and support functions such as nutrition support, support to orphans and vulnerable children, home-based care, and income generation projects. The services that are least commonly provided are shelter and placement, legal assistance, respite care, palliative care, and financial assistance.

Community organisations are at the forefront of certain areas of service delivery. A significantly greater percentage of CSOs working in the area of care and support provide services such as nutrition support, home-based care and household assistance, when compared to government institutions. Community groups are also significantly more active in providing care to orphans and vulnerable children (OVC) than are government institutions: 73% of CSOs and 71% of FBOs, compared to 13% of government institutions, report activity in this area.

Treatment

A small proportion of organisations in the survey report having a programme in HIV/AIDS-related treatment. Treatment is understood to include both clinical activities (direct interventions such as care for tuberculosis (TB), sexually transmitted infections (STIs) and opportunistic infections (OIs), and the provision of ART) and treatment-related education.

More than half (56%) of the organisations providing treatment are governmental, while 40% are CSOs. Only one FBO in the survey reported involvement with treatment activities. Relatively few CSOs are involved in administering treatment activities directly. At present, CSO activity is greatest in the area of treatment education, support for DOTS (directly observed treatment short-course) management of TB and support for the integrated management of HIV/AIDS, STIs and TB.

Communication and education

More than 80% of organisations use educational materials and communication activities as part of their work. However only 63% of organisations using IEC report being able to obtain the materials they need easily, and only 47% can obtain them in appropriate languages. Government institutions are more able to access the kinds of materials they need than are CSOs and FBOs.

The most commonly used types of materials are posters, pamphlets and guidelines. Interactive approaches to communication and education, such as door-to-door campaigns, public events and theatre are less common than informational approaches using printed materials. Public events are the most favoured form of interactive activities.

Rights and legal assistance

Approximately half of government institutions and CSOs (52% and 49%, respectively) provide some form of legal assistance to HIV-positive people. FBOs are significantly less involved in legal support for PWAs.

The most common legal activities are referral networks and support in reporting cases to the police. A smaller proportion of organisations are directly involved with advocacy for rights and in providing legal aid clinics. Only 19% of organisations providing legal services have formally qualified legal staff, while another 22% use the professional expertise of volunteer lawyers.

Training, human resources and capacity building

Sixty-two percent of government institutions, 63% of CSOs and 31% of FBOs report that they provide some sort of AIDS-related training. This includes both in-house training for staff and volunteers and training for external audiences.

The types of training which are most commonly provided are behaviour change, life skills, and counselling, while the least common types of training relate to the more specialised areas of palliative care, clinical/medical care, and legal assistance. Government and CSOs appear to be equally involved in training, except in the areas of clinical/medical training, where government institutions dominate.

Government-run training programmes tend to focus more on government employees, such as teachers and health care workers, while CSO-run trainings focus on community members and volunteers.

Many community-based AIDS response organisations draw upon the contributions of volunteers. The number of volunteers affiliated to the CSOs and FBOs participating in the survey is roughly equal to the number of full and part-time staff who work on HIV/AIDS within these same organisations. Only 10% of organisations cover the expenses of their volunteers or pay them a stipend for their contributions.

In 14% of organisations surveyed, staff work more than eight hours per day at least once a week. In 23% of CSOs and 25% of FBOs, staff work over weekends at least once per month; the proportion among government institutions is only 7%. Similarly, a greater proportion of CSOs and FBOs than government bodies (23% and 13% vs 3%, respectively) report that clients visit their staff at home after hours or over the weekend.

Financial management and funding

More than 70% of CSOs have bank accounts and bookkeepers or financial managers. A slightly smaller proportion of FBOs (56%) report having bank accounts and bookkeepers.

Forty percent of CSOs involved in AIDS response report receiving some funding from the government. No FBOs receive any funding from government.

Organisations report numerous challenges around fundraising and resource mobilisation, including inadequate funding, inconsistent flows of funding, weak systems of financial management and control, underdeveloped fundraising skills, and challenges in obtaining funding to cover salaries. The survey found some organisations, however, that cite successes in building funding partnerships.

Organisational funding profiles differ between the three sites. In Vosloorus the major funders are national and provincial departments or their surrogates; there are few examples of 'external,' non-governmental funding. In Grahamstown, 16 different CSOs report receiving funding from national and international sources, including numerous private foundations and development agencies as well as government. In Obanjeni, where there is not a critical mass of AIDS-related activity, two organisations providing AIDS-related services report that they receive funding from governmental and private sources.

Monitoring, evaluation and research

The survey found a general lack of capacity at community level for basic monitoring and evaluation activities that can inform programme development and help to quantify changing patterns of demand for services and materials.

Sixty-five percent of CSOs and 44% of government institutions monitor the number of clients that use their services. Similar proportions of organisations monitor the number of items they distribute (e.g. condoms and educational materials). Fifty-eight percent of CSOs have had their programme activities evaluated. Assessment of impact is a challenge for many community organisations.

Research is not a central activity or pursuit of most AIDS response organisations. The research work being undertaken includes basic needs assessments, canvassing of community perceptions, and service-oriented data gathering.

Coordination and networks

A majority of government institutions (83%) and CSOs (88%) report linkages with other organisations involved with AIDS response, although these linkages tend to be informal associations rather than official partnerships. The survey found a slightly lower level of networking among FBOs (50%).

Discussion

AIDS is an ecological crisis that affects all elements of a society and the way it functions, with effects felt at the individual, household and community level. Communities are mobilising and responding to aspects of the epidemic in a variety of ways, and a significant role is being played by non-state actors such as CSOs and FBOs. These grassroots responses exist in varying relationships with other HIV/AIDS initiatives, including the more centralised response frameworks led by government in particular.

The study found that CSO and FBO activity around HIV/AIDS tends to be 'general' rather than 'specialised' in nature, with more technical services (particularly medical interventions) being provided by government institutions. CSO and FBO activity emphasises face-to-face interactions with HIV-positive individuals and families, including strong emphasis on provision of psycho-social support and caregiving. Community groups appear to be responding quickly to the epidemic's changing dimensions, however. This is evidenced, for example, by their involvement in treatment literacy and education activities. Their position at community level may allow grassroots groups to see quickly and clearly where action is needed, as well as to anticipate the direction in which needs are evolving.

Community organisations have emerged as active players in AIDS response, but their activities are not necessarily well integrated with those of other local actors and the

organisations themselves face a range of institutional and developmental challenges. If the role of community-based responses is to be encouraged and strengthened, a range of issues will need to be addressed:

- The fact that much CSO/FBO activity tends to be non-technical and general, as opposed to specialised, in orientation suggests that there may be broad duplication of similar efforts within individual communities, without attention to the reach, impact or even appropriateness of these activities. As the epidemic deepens, there is a growing need for 'linked-up' networks of organisations with expertise in particular sectors of response – in other words, a shift from 'unfocused mobilisation' to more specialised, co-ordinated activity at community level;
- Low levels of project monitoring and evaluation point to a lack of clarity about the impact of activities, the public demand for particular services, and the long-term strategic role of organisations' work. Increased training in practical and easily implemented monitoring and evaluation (M&E) techniques, rather than donor-driven M&E requirements, would assist community-based organisations to focus their efforts for greater effectiveness;
- The sustainability of community AIDS response is closely interlinked with the effective management of the large number of staff and volunteers who provide frontline services within the community, often under difficult working conditions and with little or no financial remuneration. It should not be assumed that community-based AIDS response can simply be scaled up indefinitely on the basis of volunteer contributions;
- A great proportion of community organisations struggle to resource their work. Although extensive funding is available for HIV/AIDS activities, it can be difficult to access these resources and/or to meet donor requirements in relation to reporting, monitoring and financial management. Bridging the gap between the availability of funding at the macro level and the more modest resource needs of community groups at grassroots requires attention from donors and government structures in particular, both in terms of their own policies and procedures and in providing training for community groups in areas such as project design, proposal writing, record keeping and financial management.

The survey findings point to a certain tension between the day-to-day operational challenges faced by organisations – including accessing funding, obtaining needed materials and equipment, shortages of staff – and broader processes of networking and coordination that in theory could assist organisations in resolving some of these individual challenges. In none of the three sites is there a functioning mechanism for coordinating AIDS-related activities, although steps have been taken in Grahamstown to create a Local AIDS Council and ward structures in Vosloorus provide a forum of sorts for addressing AIDS-related issues. The absence of functioning coordination bodies means that services at community level are not necessarily joined up through referral networks and other coordinating mechanisms, leading to 'cracks,' inefficiencies, duplicated efforts and inadequate information sharing. Organisations working within the same general sectors are not necessarily aware of each other's work, standards and procedures are not uniform, and key services are not functionally integrated with users' needs in mind.

This suggests a need for greater coordination and integration of AIDS-related services within communities – a process that requires a deliberate and concentrated commitment by various stakeholders, including local government, to succeed. Local AIDS Councils are emerging in some localities as a forum through which various facets of AIDS response can be co-ordinated. More thorough and considered integration of AIDS-related issues into municipal Integrated Development Plans (IDPs) is another way in which multi-stakeholder responses to AIDS can be facilitated at the local level.

As grassroots activities related to HIV/AIDS burgeon in communities across the country, questions of effective AIDS governance take on ever greater importance. One important dimension of this issue is the nature of the relationship between governmental and non-governmental actors. Despite the inherent benefits of community-level responses to AIDS, and the fact that they appear to be playing the leading role in certain areas of AIDS response, they cannot operate at the scale needed to address the many impacts of the epidemic across society as a whole. However as part of mutually supporting partnerships with government agencies and other actors, they can act as a logical complement to large-scale top-down strategies. Support for effective multi-sectoral partnerships is therefore an important priority. One of the best ways to enhance the impact of community AIDS response organisations may be to focus upon partnership building at the local level – to enhance coordination between various actors, to strengthen referral networks and information sharing, and to emphasise the integration of various AIDS-related services. Strengthening ties between a diversity of groups and organisations locally may be one of best ways to facilitate collective action in relation to this enormous shared challenge.

Introduction

An estimated 5 million South Africans were HIV-positive in 2004, with the overall HIV prevalence rate estimated at 11% (Dorrington et al, 2004). The national response to HIV/AIDS in South Africa has relied heavily upon the public health system for interventions such as condom distribution, Voluntary Counselling and Testing (VCT), Prevention of Mother-to-Child Transmission (PMTCT), treatment of opportunistic infections and, more recently, the roll-out of antiretroviral therapy (ART). These initiatives have been accompanied by communication activities utilising a range of media.

However, the scale of the epidemic, the slow and/or partial implementation of certain elements of the national response, and structural limitations of the public health and welfare systems have contributed to growing community-level pressure to support and care for people living with HIV/AIDS (PWAs).

Whilst national and global policy approaches focus much attention on large-scale and centralised initiatives, relatively little notice is taken of the multi-faceted responses to HIV/AIDS that have emerged organically at local level to cope with these pressures. These responses – which range from informal support groups of relatives, neighbours, or church members, through to formalised community organisations that provide social services – are proliferating across the country. However, such activities are largely unknown outside their own localities, are inadequately recognised by policymakers, and are largely marginalised from planning and funding systems. As Foster (2002) observes: 'Few external organisations have sought to partner grassroots associations or provide them with additional resources, and few networks exist to support their development' (p. 9).

Yet there are compelling reasons to take a closer look at community-level responses to HIV/AIDS – not least because these activities are, and will almost certainly continue to be, a fundamental part of the way HIV/AIDS is lived and experienced at the local level. There is much we don't know about the extent, shape and impact of community responses to HIV/AIDS: What contributions are community initiatives actually making to the larger struggle against HIV/AIDS? What motivates individuals or groups to begin engaging with HIV/AIDS-related issues in a public or collective way? Are there certain conditions under which community responses emerge and/or flourish? Are there are ways that government or donor policies could better support and encourage such activity? Should they?

Few, if any, systematic studies have been undertaken on community responses to HIV/AIDS. However there are existing bodies of literature and conceptual frameworks that have the potential to inform such an exploration. The following section presents an overview of some of the key issues emerging from this literature, before turning to a brief review of some of the studies that have been conducted on community-level responses to HIV/AIDS in Africa in particular.

Social Capital

The way in which households and communities engage with the HIV/AIDS epidemic in its many dimensions – from prevention efforts, to care and support of PWAs and their families – can provide insight into the nature of social life within the community and, *inter*

alia, the capacity of a community to engage in collective action to address a shared challenge. The body of literature on social capital is of relevance in this respect.

The concept of social capital – the shared norms and values within a society that enable its members to engage in collective action towards the common good – has enjoyed broad application in the social sciences over the past decade (Putnam, 1993 & 2000; Portes, 1998; Narayan, 1999; Narayan & Woolcock, 2000; Evans, 1996; Foley, Edwards & Diani, 2001). First used by sociologists to describe the ability of individuals to access benefits or resources through the social networks to which they belong (Bourdieu, 1985; Coleman, 1988 & 1990; Granovetter, 1974; Loury 1977), the notion of social capital is now commonly drawn upon by economists, political scientists, development theorists and sociologists to explain why certain communities and societies may be more or less cohesive, economically prosperous, safe, and healthy than others.

The recent popularity of the term can be traced to the work of Robert Putnam, who used the concept of social capital to explain differences in local governance performance in northern and southern Italy (1993) and to highlight declines in civic-mindedness in the United States (2000). Putnam understands social capital as being largely about social networks – particularly horizontal links between people, in the form of civic institutions and associations – and the shared norms and trust which characterise them. In communities or societies with high social capital, people are more trusting and tolerant of one another, interact more, and are better able to co-ordinate themselves and cooperate in the interests of the community. Where there is low social capital, communities are likely to be more fragmented and divided.

Two main forms of social capital are noted in the literature – 'bonding capital,' which resides within relatively homogeneous groups and accounts for the closeness and solidarity of that group, and 'bridging capital,' which describes linkages that reach beyond the confines of the close community and intersect with other homogeneous groupings. It has been argued that the cohesiveness of a society is actually dependent on the existence of 'bridging capital' (or 'cross-cutting ties') as it is these relatively infrequent, but very important ties that connect disparate groups and form the criss-crossing web of interrelations between groups which underpins society as a whole (Narayan, 1999). This notion is closely linked to the theory about the important role of 'weak ties' in society (Granovetter, 1973). According to this argument, it is the relatively weak linkages that exist *between* tightly-knit groupings or clusters of individuals that prevent society from fragmenting; they allow for information and new ideas to spread across various subgroups and for collective action to emerge among them.

Development economists and political scientists have turned to the notion of social capital to account for variations in economic outcomes when the same policies are applied to societies (or communities within a society) with similar natural and human resources (Grootaert, 2001). It is suggested that social capital may shape development outcomes in terms of economic growth and poverty alleviation, even if the mechanisms through which this occurs remain poorly understood. At a micro level, it is believed that high levels of social capital may improve the functioning of markets, as economic actors are better able to share information, co-ordinate their activities and make decisions. At a macro level, at issue are institutions, legal frameworks, and the role of the state in creating an enabling environment for social capital to flourish (Grootaert, 2001).

Narayan (1999) has argued that there is a dynamic relationship between social capital, on the one hand, and the functioning of the state (and its formal institutions) on the other. She employs the notions of 'complementarity' and 'substitution' to describe this interaction. In her conception, the ideal configuration is one where the state functions effectively and is complemented by the activity of social groups (characterised by cross-cutting ties), thereby improving the overall governance environment. When government functioning deteriorates or proves inadequate for coping with new challenges, informal social activity may come to substitute for that of the state. In such contexts the relationship between state and civil society in sustaining and developing such responses is of critical importance.

While the conceptual framework relating to social capital remains very much under development, and recognising that the literature on social capital is packed with revisions and debates (cf. Portes, 1998), the concept of social capital is nonetheless potentially useful for understanding community responses to development and crisis – including the challenges of responding to HIV/AIDS.

Social capital and HIV/AIDS

Although the concept of social capital has various potential applications to HIV/AIDS, the intersection of the two remains largely unexplored and existing literature is quite fragmented. This is partly a reflection of the fact that the 'directionality' of the relationship between HIV/AIDS and social capital is not firmly established. Much has been written about the way in which HIV/AIDS may undermine social cohesion by straining households, kinship ties, and various community structures. In many societies, HIV/AIDS adds to household costs, endangers livelihoods and food security, deepens poverty, increases the vulnerability of women and children, and leads to the adoption of coping mechanisms, such as the selling of household assets, which can result in irreversible destitution. These processes may strain community safety nets, undermine extended kinship ties, and alter civic and cultural norms, including values linked to reciprocity and collective action. [1]

Others, however, argue that social capital may in fact help to prevent large-scale AIDS epidemics within societies and to mitigate the impact of HIV/AIDS in areas of high prevalence. Linkages have been made between levels of social capital and public health. It has been argued by some that societies with high social capital and social cohesion may have better overall population health (Kawachi, 2001; Wilkinson, 1997). Wilkinson's work, for example, has suggested that relative economic equality within a society is more important determinant of positive health outcomes than are the absolute levels of wealth or poverty (1997).

The pathways through which social capital may act to shape health are contested, but may include social networks (sharing of health-related information; emotional and physical care and support), civic engagement and activity (community advocacy on health issues and needs), and normative processes that shape health-related behaviours and lifestyle choices and bolster people's sense of self-efficacy.

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[1] For a review of key issues related to the local impact of HIV/AIDS in Africa, see *Community Realities & Responses to HIV/AIDS in Sub-Saharan Africa*, produced by the United Nations Office of the Special Adviser on Africa (OSAA), 2003.

From a slightly different perspective, it has been suggested that stable democratic societies with strong civil societies, high levels of social cohesion, and good governance practices may be less likely to experience severe HIV/AIDS epidemics and better equipped to respond to an epidemic, should one occur (Barnett and Whiteside, 2002; Nelufule, 2004). The reasons posited for this possible link include the greater legitimacy of democratic governments as sources of information on HIV/AIDS, higher public awareness of the epidemic as a result of free speech and free press, and higher levels of social trust and civic activity, which facilitate collective action (Mattes, cited in Manning, 2002). Others have pointed to established legal systems, a culture of human rights, the empowerment of women, and civic demands for transparent and accountable government as factors that could reduce HIV-related discrimination, create a culture of openness, and encourage strong leadership on the issue (Whiteside, cited in Manning, 2002). Still others have pointed to the lobbying and advocacy role played by civil society organisations, such as South Africa's Treatment Action Campaign, in shaping official responses and policy in relation to the epidemic (UNDP, 2003).

Most such works are theoretical or conceptual in nature; there is limited empirical data available to support or refute such speculation, or to provide insight into how such linkages might operate in practice. In South Africa, one of the few studies to date was undertaken by Campbell, Williams and Gilgen (2002), who investigated whether there is a link between associational membership and HIV prevalence in a large South African township. The study found that HIV prevalence was lower among some age and gender groups belonging to specific types of associations (such as sports clubs), but was higher among those belonging to other groups, such as *stokvels* (savings associations). Their findings may reinforce concerns about 'negative social capital' – *stokvels*, for example, were linked with alcohol consumption and a greater likelihood of sexual activity with casual partners (Campbell, Williams & Gilgen, 2002).

Noting the various structural determinants of HIV transmission in South Africa (poverty, migration, and gender inequality), Pronyk (2002) has suggested that strengthening the stock of social capital in South African communities could mitigate against HIV transmission and impact. According to Pronyk, social networks may help to diffuse health-related information (e.g. in relation to risk reduction), to shape community norms and showcase positive role-modelling behaviours, and to provide members with material, emotional and social support which ensure a measure of stability and could therefore mitigate against high-risk behaviours. Communities with high social capital may also be more able to advocate for people's health needs, create a more tolerant and positive environment for PWAs, and join together to undertake collective action in response to challenges.

The possible links between social capital and HIV/AIDS – particularly the 'positive' effects of social capital in curbing the spread of the epidemic – have been discussed more extensively in the case of Uganda, which is widely held up as an example of a society in which broad-based social mobilisation has helped to curb the spread of the epidemic. Thornton (2003) has chronicled the unique synergy of governmental and community action that emerged in Uganda during the early stages of the epidemic, paying particular attention to the role of community networks, churches and other structures in spreading information about HIV/AIDS, supporting infected individuals and families, and reducing stigma. Thornton argues that the success of the Ugandan response can be attributed to the open and proactive position of the Ugandan government in relation to the epidemic, a

decentralised approach which devolved control over AIDS programmes to the grassroots, a free press which openly addressed AIDS, the active engagement of religious communities, and the proliferation of grassroots AIDS-related organisations such as TASO – The AIDS Support Organisation – which is regarded as one of the most successful examples of civil society response to AIDS. According to Thornton (2003), 'Major international donors provided most of the financial resources, but very little of the actual implementation. Overwhelmingly, Ugandans themselves identified the problems, generated solutions, and integrated these into close knit networks of mutual support that brought to bear the concerted action of society at large' (p. 2).

Jamil (2004) has also considered the role of social capital and community responses to AIDS in Uganda, arguing that non-governmental organisations (NGOs) concerned with fostering social relations between PWAs and broader communities (as opposed to more 'individualised' approaches to HIV/AIDS, such as counselling and testing) have played a crucial role in building social capital in the Ugandan context. Organisations such as TASO – which emphasise social support, empowerment, care, and reduction of stigma and exclusion – have helped to facilitate the inclusion of PWAs, have made a difference in the lives of their beneficiaries, and have promoted social solidarity in a country strongly affected by the epidemic. He argues that such processes of social capital building on the part of civil society are critical for maintaining an inclusive society, and that the state must do its part to facilitate and encourage such work by non-governmental actors.

Community Responses to HIV/AIDS

The Ugandan experience has highlighted the important role that community-level AIDS initiatives can play along the continuum of prevention, care and support, treatment, and rights. This finds corroboration in an emerging literature around HIV/AIDS and community-level responses, comprised of both theoretical reflections on the role and impact of community activity and a limited number of studies that have attempted to map the configuration of local-level responses within particular areas or sectors of work.

On a conceptual level, community-level responses are seen as immediate, direct, and flexible; they emerge from local conditions, are driven by community members, are responsive to local needs, reflect local forms of organising and acting, and draw upon available resources (OSAA, 2003; Goudge et al, 2003). Although often small-scale in nature, their cumulative impact should not be underestimated (Foster, 2004). Beyond addressing specific needs, community activity also can foster empowerment and lead to social change (OSAA, 2003). As Jamil (2004) has noted in relation to AIDS-related organisations in Uganda, by encouraging dialogue, mutual support and collective action 'organisations have developed and successfully promoted perspectives that go beyond self to civic responsibilities' (p. 18).

Community responses to HIV/AIDS come in many varied forms which do not lend themselves to simple definitions or typologies. In the literature a distinction is often made between informal grassroots initiatives and more formalised activities, such as those of community-based organisations (CBOs), non-governmental organisations, and faith-based organisations (FBOs).[2] Mutangadura *et al* (1999), in a review of household and

[2] Increasing attention is paid, both within Africa and internationally, to the role of faith-based organisations (FBOs), which are seen as uniquely positioned to provide care and support to affected individuals and families and to

community responses to HIV/AIDS in rural southern Africa, distinguish between informal community groups, which keep few documented records of their activity and have low organisational costs; indigenous CBOs, which form locally in response to shared experiences; and NGOs, which tend to be formed by and operate with the help of external funders or allies. NGOs are often seen as playing a developmental and capacity-building role in relation to CBOs, as well as sometimes serving as funding conduits and engaging in policy-making and advocacy activities.

A similar 'spectrum' of activity – ranging from the informal through to the more structured – is depicted by Foster (2002) in his work on community support to orphans and vulnerable children. Foster describes the spontaneous, informal and 'ordinary' actions that are undertaken within African communities to support orphans and vulnerable children who may be slipping through the traditional safety net of the extended family. He notes that 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' (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; voluntarism (altruism emanating from sense of community ownership); innovation/problem-solving; and association with faith-based organisations.

In some instances, informal groups expand the size or scope of their activities and become more formalised. Signs of this include the establishment of committees, collection of membership contributions or donations, introduction of income-generating activities, approval of statutes, opening a bank account, and offering training activities (Foster, 2002).

Similar insights come from Teljeur (2002), who reviewed literature on community and NGO responses to HIV/AIDS in South Africa. She found in the literature a general consensus that CBOs and NGOs play an important role in helping families and communities cope with the impacts of HIV/AIDS, but that the approaches used often vary and are difficult to systematise. Teljeur stresses that the form of each initiative is community-specific, but suggests that there are certain similarities in the way responses evolve across communities: they begin as coping strategies within the family (e.g. asset/income diversification, savings schemes, help from networks, food production) and then evolve into a greater reliance upon outsiders and general community resources (Teljeur, 2002). More formalised community responses include labour sharing schemes, day car services, orphan support, community-based health care, home-based care, income generation projects, and credit schemes.

Growth in AIDS-related community activity should be seen as part of a broader pattern of civil society activism evident in many parts of the world over the past two decades. As many states scale back their role in service delivery as part of market-friendly

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spread messages about HIV risk and prevention through their constituencies, some of which are located in remote and hard to reach areas (Nelufule, 2004; Liebowitz, 2002; Foster, 2004).

macroeconomic policy shifts, civil society institutions of various types and orientations have taken on a more prominent role both in addressing local needs directly and in advocating for policies that contend with the factors underpinning such needs. Non-governmental organisations have become increasingly popular vehicles for development assistance, as they are perceived as more flexible, less bureaucratic, closer to the ground, and more cost-effective than large-scale governmental or multilateral initiatives (OSAA, 2003; Jamil, 2004).

Yet community initiatives cannot and should not be seen as an alternative to the state in issues of development and service delivery. Local initiatives, although powerful collectively, lack political-economic leverage and are therefore most successful in cases where they are either supported by or partnered with the state (OSAA, 2003). The state has an important role to play in facilitating an enabling environment for civic groups to do their work, for example in terms of conducive taxation and regulatory regimes, and in ensuring freedom of association and expression.

While much positive can be said about the resilience of communities in response to AIDS, it is important not to romanticise their role. Local-level responses are not a panacea for a phenomenon as complex and multi-faceted phenomenon as AIDS, and the constraints that limit the impact of community initiatives have been noted by many observers. These can include resource constraints, operational inefficiencies, limited outreach (both in terms of geography and number of beneficiaries), inadequate consultation and engagement with community members, competition with other groups over resources, and dependency on external funding for sustainability (OSAA, 2003; Jamil, 2004).

Studies on community responses to HIV/AIDS

There have been a small number of attempts to 'map' and assess community-level responses to HIV/AIDS in Southern Africa, although it should be noted that these vary greatly in focus, scale and approach. Nonetheless, the findings of these studies highlight some important dimensions of community response and merit a brief overview.

UNICEF and World Conference of Religions for Peace (WCRP) conducted a six-country study of the work of faith-based organisations in supporting orphans and vulnerable children (OVC) (Foster, 2004). On the basis of interviews with 690 FBOs[3] in Kenya, Malawi, Mozambique, Namibia, Swaziland and Uganda, the study identified close to 350 initiatives that support more than 150,000 OVC, drawing upon the help of more than 9000 volunteers. The study's authors estimate that this represents only a tiny proportion of the faith-based work with OVC occurring in the six countries studied. Eighty-two percent of the initiatives identified are occurring at community level, through small congregation-based projects supporting less than 100 children on average. More than half of these initiatives have been established since 1999; most have been initiated by community members themselves and do not receive any external support. The main activities in which the FBOs are involved are material support, provision of medical care, income generation schemes, day care centres, home-based care, school assistance, HIV prevention, and counselling and psycho-social support.

[3] In this study FBOs included local level congregations, 'religious coordinating bodies,' faith-based NGOs and CBOs.

The main conclusion of the study is that local-level FBO involvement with OVC is flourishing, that individual congregations are supporting significant numbers of OVC, that the initiatives are expanding rapidly without financial and technical assistance, and that, contrary to assumptions, the work is well-organised and not under-capacitated administratively. The research also found, however, that there is a need for financial support and that 'religious coordinating bodies' (denominational structures that support congregations) are well-placed to play a more significant role in supporting congregation-level work. The authors of the study conclude 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 than are large, external agencies (Foster, 2004).[4]

In a rapid appraisal of community-level care and support services available for PWAs in South Africa, Russell and Schneider (2000) note that localised projects are emerging across the country to fill the gaps in formal services, including support groups, outreach to OVC, and home-based care. Russell and Schneider found that most of these initiatives are in their infancy and quite 'precarious,' operating with limited resources and little external support. They point out that there are no guidelines or uniform standards relating to quality of care within the sector. Key challenges include recruiting and managing volunteers and accessing resources. They note, however, that the most successful and sustainable initiatives were those that had established partnerships and referral relationships with other local programmes, and that operated in communities with high levels of social cohesion.

A small-scale study in the Amajuba District Municipality in KwaZulu-Natal sought to identify the various types of child welfare organisations (including those providing OVC support) that exist in the area and the services that they provide (Jurgensen, n.d.). The research found 15 different organisations – predominantly CBOs and NGOs – that are involved with child welfare work. Despite the fact that these organisations work in the same municipality on similar issues, they were largely unaware of each other's work and tended to operate within small professional networks. There was no forum or initiative to co-ordinate the work of groups supporting OVC, and most NGOs and CBOs reported that they did not network with others and did not see this as a constraint.

Another area of focus has been the role of community-based health workers (CBHW) in providing care and support for PWAs, including assistance with ART regimes. Using interviews and focus groups, Campbell et al (2005) have developed a case study of HIV/AIDS management in a deep rural area of KwaZulu-Natal in order to explore the potential role for community-based health workers in relation to effective ART roll-out. They found that grassroots health workers already play a critical role in the provision of health-related services in the area, including home-based care for individuals dying of AIDS. These volunteer carers perform a range of functions, from counselling to direct care-giving, but do not always have AIDS-care treatment, do not have supplies and materials, and do not receive compensation for their work. The authors argue that such

[4] For discussion of the ways in which external agencies can best support local-level work with OVC, see Richter, L., Manegold, J. & Pather, R. (2004) *Family and community interventions for children affected by AIDS*. Cape Town, Human Sciences Research Council, pp. 19-20.

volunteer carers exist in many communities across South Africa and represent an already mobilised, but under-utilised resource for AIDS support.[5]

Finally, a report developed by the Centre for Health Policy in Johannesburg (Goudge et al, 2003) identifies various models for government funding and support of NGOs, FBOs and CBOs that provide home-based care services on the basis of South African and international experience. Premised on the belief that community-level home-based care will continue to be a critical component of national AIDS response in South Africa, it explores the practices of two large South African NGOs that support community-level health provision (Project Support Association of South Africa and the AIDS Foundation) to identify ways that the 'weaknesses' of local-level initiatives (e.g. limited financial resources, limited skills and capacity) could be addressed and overcome within a national home-based care roll-out. The authors of the research conclude that community-based organisations need technical and organisational support, as well as funding, to be effective and that there is a danger that high turnover of un-compensated volunteer caregivers may lead to organisational 'churn', instability and reduced effectiveness. However they stress that a considerable body of experience already exists on community home-based care and that this expertise should be drawn upon in scaling up home-based care nationwide.

Issues for Investigation

As this brief literature review shows, there has been little systematic study of community responses to HIV/AIDS. Much of what is known is descriptive and comes from reports by non-profit organisations, development agencies and project managers working at community level. In many cases, these reports focus on particular types of response, such as programmes for orphans and vulnerable children or home-based care programmes. Little if any research has been undertaken on quantifying community responses as a whole and on exploring how they interface with other types of activities within a given community.

The given research was initiated to investigate the scope and scale of community responses to HIV/AIDS as part of a process of better understanding the possibilities for linking organic local level responses into a supported, sustainable, co-ordinated and ultimately integrated system of responses that combines the efforts of state and community.

[5] For a more detailed discussion of community-based health workers in South Africa, see Friedman, I. (2002) Community Based Health Workers. In: *2002 South African Health Review*. Durban, Health Systems Trust.

Methodology

Research Questions

The study was designed to explore how local communities are responding to HIV/AIDS. Key questions for investigation include:

- What HIV/AIDS-related initiatives and activities are operating in the participating communities, who implements them and how have they grown over the years? Which sectors are responding to the epidemic at local level and what is the range of HIV/AIDS-related services being provided through these initiatives?
- What type of training and internal capacity building do these organisations provide for their staff and/or volunteers? Who provides training to them and what areas of training have they been exposed to?
- What approaches have been used by local organisations to communicate their messages and programme activities to local populations?
- What capacity exists to deliver, sustain and further develop these programmes or activities? Are there management and organisational systems? What kind of support structures exist? Who provides funding and how successful are organisations in accessing funding?
- What are the challenges facing these initiatives at local level and what successes have been experienced?
- Are there coordination mechanisms in the communities that link up the work of AIDS-response organisations? Do the organisations network with each other? Are there referral systems? To what extent are AIDS responses integrated and cohesive at community level?
- What is the relationship between indigenous community responses to AIDS and services provided by the public sector in a more centralised manner? Do they intersect? Is the relationship one of complementarity or substitution?
- What conditions seem to encourage community responses?

Research Context

The study was undertaken in three communities: Vosloorus, an urban township in Gauteng Province; Grahamstown, a small town in the Eastern Cape; and Obanjeni, a deep rural area of KwaZulu-Natal.

The selection of these communities was based on two main factors. First, the three sites are distinct from one another in terms of size, type, population density, geographical location, and other characteristics. This potentially allows for observation of variation between types of communities and local responses therein. Second, CADRE has previously conducted work on local responses to HIV/AIDS in these communities and has developed relationships with local leaders and organisations that facilitated research access.

Vosloorus

Vosloorus is a large urban township that is part of the Ekurhuleni Metropolitan Municipality, on Johannesburg's East Rand (Gauteng Province). It is a densely populated area with a total population of just over 150,000; 99.8% of the population of Vosloorus is Black African.[6] IsiZulu is spoken by 48% of the population, while Sesotho is spoken by 19%. Thirty-seven per cent of the population of Vosloorus is under 20 years of age; 54% of the residents are between 20 and 49 years of age.

Vosloorus is a well-developed township comprising five electoral wards. Seventy-two percent of the population lives in a house or brick structure on its own stand (predominantly government 'matchbox' houses); 8% live in a flat or a room in a back yard; 6% live in informal dwellings or shacks; and 5% live in blocks of flats (hostels). Ninety-two per cent of dwellings in Vosloorus are connected to sewer systems. Only 25% of households in Vosloorus have telephones (landlines); 26% of households have only cell phones and 44% of households use public telephones.

Like many South African communities, Vosloorus is facing the interlinked challenges of unemployment, poverty, and HIV/AIDS. Among the working age population (15-65 years old), 60% report having no monthly income, 32% of people earn less than R3200 per month, and only 8% earn more than R3201 per month. Thirty-six per cent of Vosloorus residents aged 15 to 65 are employed and 15% are students. Forty-one percent describe themselves as unemployed or unable to find work.

Grahamstown

Grahamstown is a small town in the Eastern Cape that falls within the boundary of Makana Local Municipality, which is part of the Cacadu District Municipality. The Grahamstown site is comprised of the town centre and two outlying townships. The total population of the area is 61,747.

Seventy-eight per cent of the population of Grahamstown is Black African, 12% is Coloured, and 10% is White. IsiXhosa is the predominant language in Grahamstown, with 75% of residents reporting it as their first language; Afrikaans is spoken by 13% of residents and English by 11%. Thirty-nine per cent of the population of Grahamstown is under 20 years of age and 45% is between 20 and 49 years of age.

Grahamstown is an old town dominated by a business district and university in its central area and the townships of Rhini and Fingo Village on its outskirts. Some of the housing in Rhini and Fingo Village was built as part of the Reconstruction and Development Programme (RDP), but the townships are long-established and many of the buildings date back 40 or more years.

Fifty-five per cent of people in Grahamstown live in houses with their own yards, 15% live in traditional dwellings or structures, and 10% live in informal housing or shacks. There are more households in Grahamstown that use bucket or pit latrines (58%) than those that have flush toilets connected to sewerage systems (34%). Approximately one-third of households in Grahamstown have telephones (land-lines); 36% of households use public telephones nearby.

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[6] Figures used in descriptions of sites drawn from the South African Census (2001), Statistics South Africa.

Among the working age population (15-65 years old), 62% report having no monthly income, 32% of people earn less than R3200 per month, and only 8% earn more than R3201 per month. Twenty-seven per cent of Grahamstown residents aged 15 to 65 are employed and 24% are students. Thirty-four percent describe themselves as unemployed or currently unable to find work.

Obanjeni

Obanjeni is a deep rural area located in the northeast of KwaZulu-Natal. The area falls within the jurisdiction of uThungulu District Municipality and has a population of approximately 8000-10,000 people. Obanjeni is a developing area constituted by few scattered homesteads, known as 'imizi.' It is headed by a Tribal Authority or 'inkosi.'

The area is characterised by inadequate infrastructure. Access to electricity, clean water, and sanitation are still problematic, and the roads in the area (all gravel) are poorly maintained. Institutions such as schools, community halls, shops, and churches are few in number and scattered at a distance from one other. Like many parts of rural South Africa, Obanjeni is facing high rates of unemployment, poverty, hunger, and HIV/AIDS.

Research Approach

A community audit was undertaken using a structured questionnaire administered by field researchers. Institutions and organisations providing AIDS-related services, or involved in HIV/AIDS activities, were identified, approached, and interviewed. Snowball techniques were employed in an attempt to identify all actors involved with AIDS response in each community. Additional research included in-depth interviews with selected key informants in each community to understand the key issues of municipal response, including co-ordination and integration of local activities.

Research access to the three communities was negotiated through local leaders. Permission to conduct research was obtained through key authorities in the community, including various government departments, local government authorities, NGOs and traditional leaders. Where possible, presentations about the project were made to community members through local groups. This approach also proved helpful in terms of identifying structures existing in each community

Development of instruments

The questionnaire used in the community audit was adapted from a survey instrument previously developed by CADRE personnel and published in *Local Government Responses to HIV/AIDS: A Handbook* (World Bank, 2003).

Sections of the questionnaire covered the following areas:

- Demographic profile of organisation
- HIV/AIDS prevention activity
- Care and support for PWAs and affected families
- Treatment
- HIV/AIDS training
- Rights and legal assistance

- Organisational networks
- Staff
- Funding and research
- Communication and education

Data collection, capture and analysis

Data collection was done by CADRE researchers with assistance from field workers from each community. Survey administrators were trained in questionnaire use and survey administration.

Informed consent was obtained from individuals who were interviewed. All information in the survey pertaining to staff and interviewees was kept anonymous and confidential.

The data was captured in SPSS and cleaned before analysis. Certain variables were grouped and recoded to facilitate analysis.

In-depth interviews were conducted by CADRE senior researchers in the three communities. Most interviews were taped and transcribed; in the remaining interviews notes were taken and written up.

Limitations of the Study

Certain limitations to the survey instrument became apparent at the stage of analysis. Many organisations do not focus on HIV/AIDS as their primary activity and it was sometimes difficult to separate HIV/AIDS responses from other activities conducted by respondent organisations. Some of the information required (e.g. number of workers involved in full-time HIV/AIDS activities) proved difficult for respondents to provide. Often organisations had not sufficiently clarified their own objectives or had not reflected systematically on the challenges they faced, so that responses to these questions were frequently vague and undetailed.

We limited our data collection to those formalised social groupings and agencies. We did not attempt to capture the more informal responses that exist at community level, and also excluded from analysis responses from groupings operating with a profit motive. In Vosloorus for-profit organisations were initially included in the survey, but the inclusion of, for example, street vendors that sell condoms tended to confuse our primary purpose of understanding community-led responses to HIV/AIDS. There is no doubt value in understanding the responses of the business community, including private medical practitioners and workplace initiatives, but such activities were deliberately not included in this study.

We ultimately decided not to report school responses to HIV/AIDS, although information on this was collected in some sites. The reason for the exclusion is that this data is difficult to interpret as it ranges from preschool to tertiary institutions and includes both private and state institutions. Although worthy of its own study, the data could not be readily incorporated into a comparative analysis with the other categories used in the analysis: state, CSOs and FBOs.

The sample sizes across the three communities differ significantly. It should be noted that the sample size in Obanjeni is particularly small – only eight groups involved with AIDS response were identified. In Vosloorus, by contrast, 104 organisations or formations were identified. It is thus problematic to simply aggregate the data for analysis, because the dynamics of interaction in Obanjeni, which are in many respects different to those in Grahamstown and Vosloorus, are lost in aggregation. In spite of this, we tend to aggregate the data as a general rule, but in writing the report have focused separately on individual sites in cases where notable differences in findings emerged.

A final limitation in the study is that the field of community HIV/AIDS responses is dynamic and shifting. We conducted this study around the time that antiretroviral therapy (ART) was beginning to be introduced across South Africa. There can be no doubt that the introduction of ART is changing the landscape of community HIV/AIDS responses in manifold ways (Kelly & Mzizi, 2005). Were we to do this research now, we would almost certainly find a much greater concern about HIV/AIDS treatment issues. Nonetheless, the survey provides valuable insight into many of the other challenges of developing adequate, efficient, systematic and sustainable community-level responses.

Research Findings

Community Actors

A diverse range of organisations are involved in some way with AIDS response, and many organisations responding to AIDS do not work exclusively in the AIDS field. Some may provide support services in a selective way as an off-shoot of their core activity (for example, provision of legal services), while others may have become involved in AIDS response in recognition of the epidemic's impact upon their constituency (e.g. churches). In assessing 'who is doing what and where,' it is important to take the broadest possible view of who the actors are in order to gain a perspective of the range of resources which contribute to the totality of AIDS responses in a particular community. This report focuses in particular upon the activities of government institutions, non-governmental and community-based organisations, and faith-based organisations.

Profile of HIV/AIDS responses

The organisations identified in the survey have been categorised into a number of discrete types. Government organisations represent an aggregation of local, provincial and national government institutions engaged in some way with HIV/AIDS at the local level. These include institutions as varied as government departments (e.g. social development, health, child welfare), clinics and hospitals, police and correctional services, and municipal-level administrative structures.

Civil society organisations include those organisations that designate themselves as non-governmental (NGO), community-based (CBO), non-profit (NPO), dedicated women's, youth or political organisations and social service clubs. This category encompasses a large number of community-based AIDS initiatives (e.g. home-based care organisations, support groups) and PWA associations, as well as hospices, women's and men's groups, training organisations, youth outreach groups, community centres and non-AIDS specific associations such as Black Sash, FAMSA, and mental health councils.

Organisations identifying themselves as faith-based have been categorised separately. These are almost exclusively local (Christian) congregations.

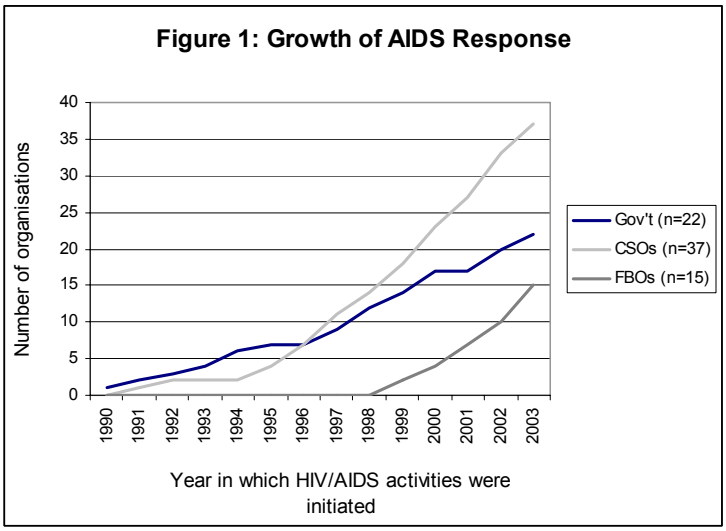
Among the 179 organisations identified in the three sites, 43 are civil society organisations, 29 are government agencies, and 16 are FBOs.

Given that these are quite broad categories that encompass entities of various sizes and types, there are limitations to the direct comparisons that can be made between these sectors. However, it does suggest that AIDS response is a broad social concern at community level and that there is a substantial amount of non-public activity in relation to AIDS which needs to be considered in taking stock of the scope and scale of AIDS responses in society.

Growth of HIV/AIDS responses

Figure 1 represents the cumulative number of organisations involved in AIDS responses through 2003, according to the year in which organisations first began HIV/AIDS activity.

Just over half of these organisations have become involved with HIV/AIDS response over the past five years. Whereas the number of government organisations involved in AIDS response has risen at a fairly even rate, the growth of CSO and FBO responses has risen more steeply. Since 2000, there has been a 29% increase in HIV/AIDS initiatives among government agencies compared to a 61% increase in CSO activity and a 275% increase in FBO activity.



Note: Not all organisations (74 out of 88) answered the question about the year in which they were established.

There is corroboration of this finding in the database of non-profit organisations registered with the Department of Social Development,[7] and also in the National AIDS Database compiled by the Centre for HIV/AIDS Networking (HIVAN) at the University of KwaZulu-Natal for the Department of Health. Analysis of the National AIDS Database, which contains information about organisations across South Africa which are involved with AIDS-related activities, shows that the number of NGOs and CBOs involved with AIDS activities has risen by 108% between 1995 and 2004, while the number of FBOs has risen by 133%.[8]

Similar patterns of growth in CSO activity in relation to AIDS have been seen in Uganda, where the number of HIV/AIDS organisations (dealing wholly or in part with HIV/AIDS) registered with the Uganda Network of AIDS Support Organisations grew from 13 in 1979 to 265 in 2003 – a more than 20-fold increase (Thornton, 2003).

It is unlikely that this trend will abate. As the epidemic deepens its impact on communities, the dual challenges of care/support and treatment will likely draw further on civil society resources. At present, existing government facilities are being used to develop and administer treatment programmes, but it is evident that a range of services are required to support treatment services. In many instances, agencies other than government health departments are best equipped to deal with these needs, or are

[7] Accessible at http://www.welfare.gov.za/NPO/npo.htm

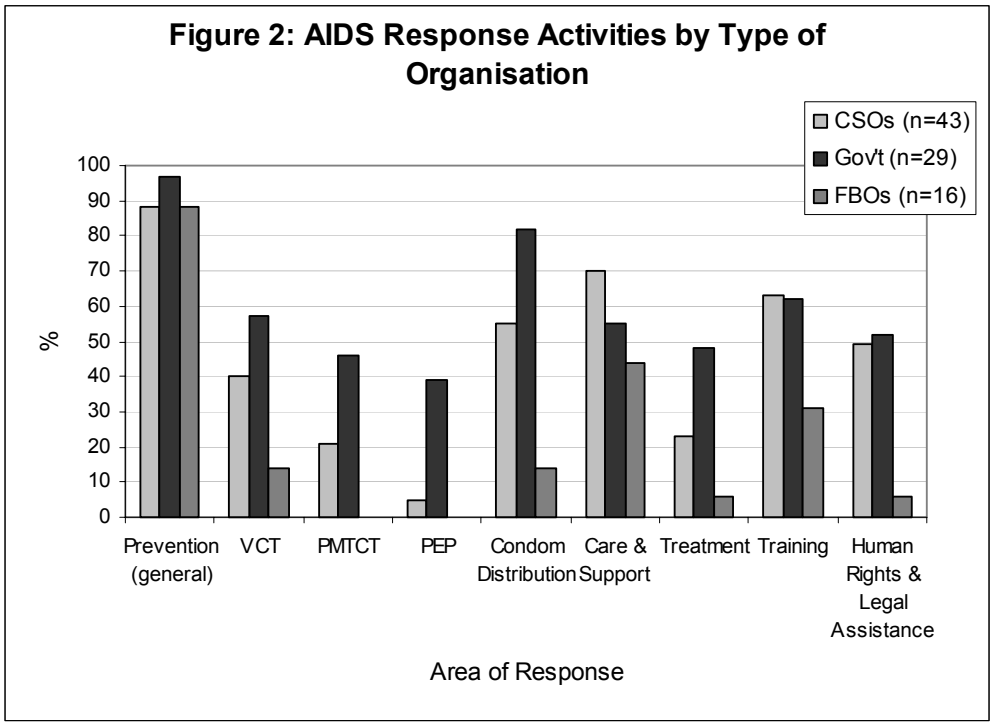
[8] In March 2005, the National AIDS Database contained more than 750 records for NGOs/CBOs and more than 160 records for FBOs. Analysis of National AIDS Database conducted by CADRE (unpublished).

dealing with these needs in the absence of sufficient government action in the area (cf. Kelly & Mzizi, 2005).

This trend is not yet visible in the data, which was collected from late-2003 to mid-2004, and which reflects that civil society and faith-based organisations are not yet strongly involved in administering treatment programmes. However, the data from this study shows that they are already heavily involved in providing complementary care and support services. These questions are discussed further in the sections on care and support and treatment.

Intervention focus: overview

Below we present a broad profile of type of HIV/AIDS-related activities with which CSOs, FBOs and government agencies are involved. Specific areas of intervention are explored in greater detail in subsequent sections of the report. This brief discussion is intended to overview the relative proportion of involvement in different areas of intervention.



The survey asked organisations about five broad areas of HIV/AIDS activity: prevention, care and support, treatment, training and legal assistance. As Figure 2 shows, prevention activity[9] is undertaken by the greatest proportion of organisations: 88% of FBOs, 88% of CSOs and 97% of government organisations engage in some form of prevention activity. When disaggregated by specific prevention interventions,[10] it is apparent that higher proportions of government organisations than CSOs and FBOs are involved in provision of the more technically oriented services, such as VCT, PMTCT, and PEP. Condom

[9] In Figure 3, the first column – 'Prevention' – is a generic category which subsumes the categories of VCT, PMTCT, PEP, and condom distribution, as well as a range of other prevention activities such as life skills education and behaviour change training.

[10] Among those FBOs, CSOs and government agencies that are involved with prevention activities.

distribution is relatively frequently reported among government agencies and CSOs, but is less widespread among FBOs.

Care and support is the only direct service area where CSOs are significantly more involved than government agencies. Seventy percent of CSOs report providing care and support services, compared to 55% of government agencies.

The survey found that the proportion of CSOs and FBOs involved in treatment is relatively small, and that treatment activity remains centralised in government institutions. This will be an important area of response to track in future as the national treatment initiative unfolds.

The survey found that a similar proportion of CSOs and government agencies – 63% and 62% respectively - are involved in providing HIV/AIDS-related training. Training is conducted by 31% of FBOs.

Human rights and legal assistance is also an area of activity for quite a large proportion of organisations. This does not necessarily imply high levels of technical competence in legal or human rights matters – it may involve referral services, guidance in seeking legal recourse, or assistance in applying for grants, for example. It does show, however, that there has been a generally high level of recognition of the need for support in this area and accompanying response to the need.

Figure 3: Characteristics of AIDS Response Organisations

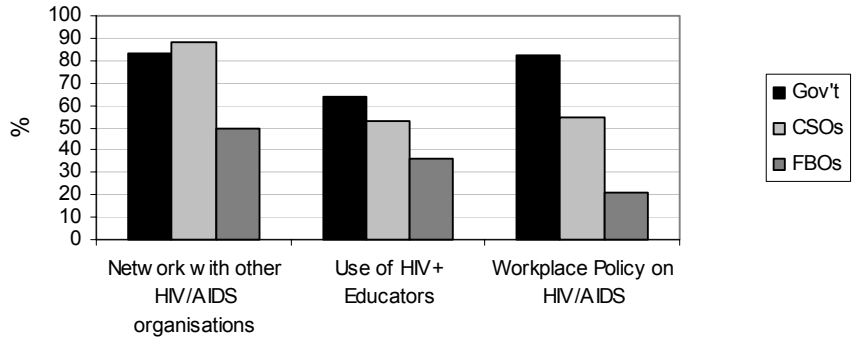
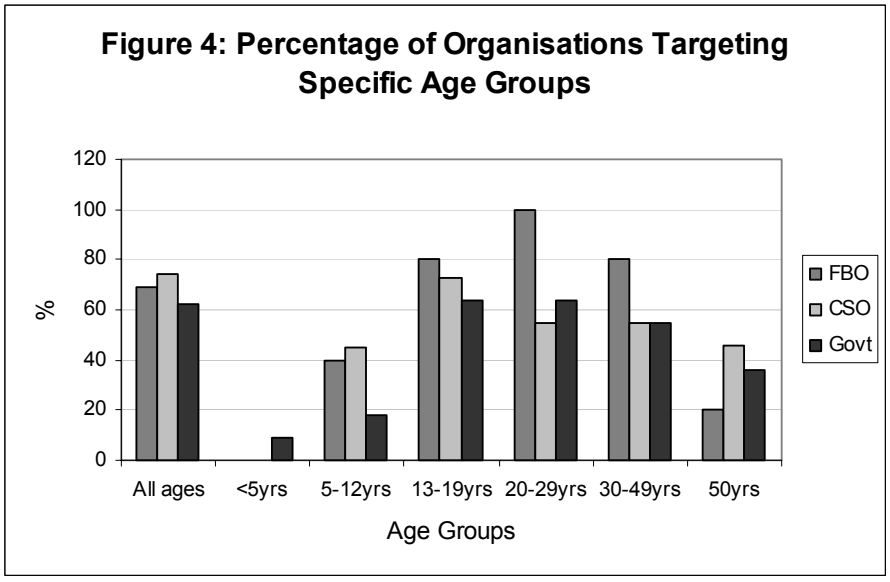


Figure 3 presents data on some general characteristics of AIDS response organisations – the extent to which they network with other organisations, whether they use HIV-positive individuals as educators, and whether they have a workplace HIV/AIDS policy in place. More than 80% of government agencies and CSOs report that they network with other organisations, compared to 50% of FBOs. Government agencies were more likely than CSOs and FBOs to use HIV-positive educators and to have a workplace AIDS policy.

Age focus of AIDS response

Figure 4 represents the target age groups with which various types of organisations work.



Most government agencies, FBOs and CBOs tend to work with all age groups, as reflected in the first column of the chart.

The age-specific columns (columns 2-6) exclude the responses of the majority of organisations which report working with all ages. The number of organisations that work only with specific age groups is quite small (FBO – 5; CSO – 11; Govt – 11). The percentages reported under specific ages in Figure 3 are the percentage within this sub-sample that work with a particular age category or categories, rather than with all ages.

Most of the age-specific efforts are concentrated on the 13-49 year age range, which covers the age of reproductive capacity. The age range of 13-19 years enjoys the widest coverage where organisations focus on specific age groups. Interestingly, faith-based organisations tend to target specific age categories more than the other two types of organisations, and apparently have a more differentiated approach to programme development, which is related to age and presumably life stages.

Prevention

Efforts aimed at preventing the spread of HIV are at the core of many AIDS response strategies. Prevention activities seek to bring about individual behaviour change by encouraging people to learn their HIV status, to take precautions not to transmit HIV to others if they are positive, and to protect themselves against HIV infection if they are negative. The success of prevention activities depends not only on raising people's awareness of HIV/AIDS – although this is a necessary prerequisite – but also in teaching people how to integrate knowledge about HIV risk into their own lives and contexts.

Organisations were asked about activities they undertake in relation to HIV prevention. Those organisations that were involved in prevention activities – defined broadly to include both general prevention education (e.g. life skills training, behaviour change

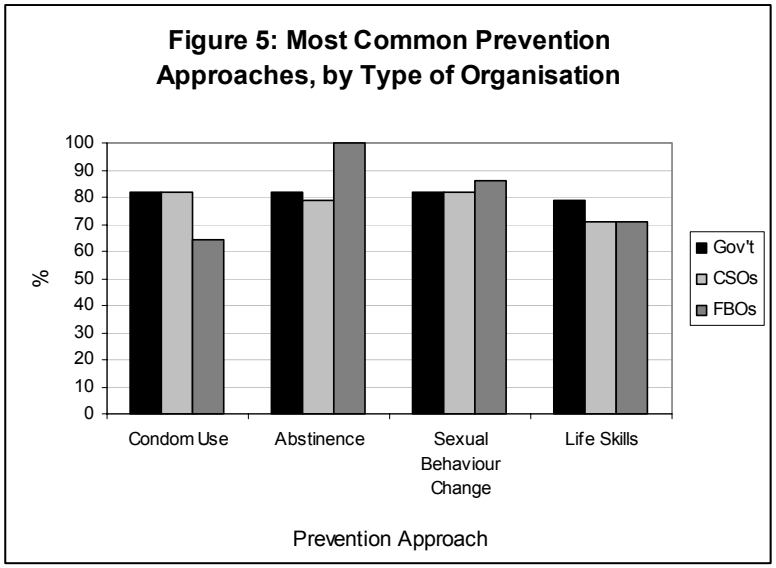
programmes) and specific interventions (e.g. condom distribution, counselling and testing) – were asked about the target audiences for their work, their prevention focus, and any work relating to four specific interventions: VCT, PMTCT, PEP, and condom distribution.

Approaches to Prevention

Prevention activity is broad-based and extends across different organisational types. The survey results show that, as a whole, AIDS response organisations are more active in prevention work than in any other area of response. Ninety-seven percent of government institutions, 88% of CSOs, and 88% of FBOs are involved with prevention work.

Prevention activities vary by type of organisation, and certain types of response are more widespread than others. Among CSOs, FBOs and government institutions, the four most commonly cited areas of prevention work are promotion of abstinence, sexual behaviour change, condom use, and life skills. However, the relative emphasis placed on these approaches differs by type of organisations. Figure 5 shows the percentage of government institutions, CSOs and FBOs that emphasise these four approaches.

Figure 5: Most Common Prevention Approaches, by Type of Organisation

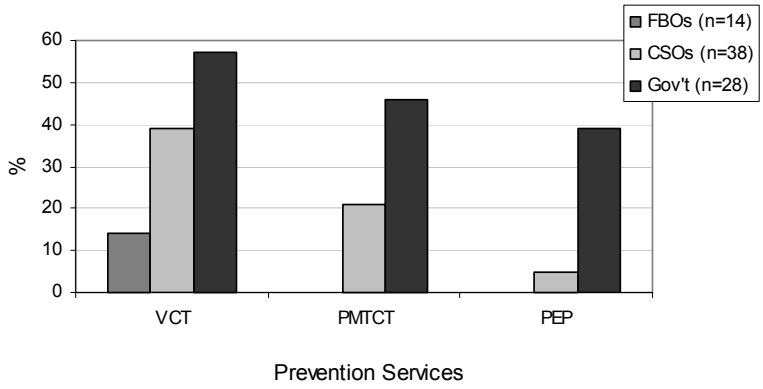


It is apparent in the above chart that FBOs tend to focus more on abstinence and sexual behaviour change than on condom use. Only 64% of FBOs promote condom use and an even smaller proportion (14%) distribute condoms.

Government organisations emphasise sexual behaviour change (82%), abstinence (82%), condom use (82%), life skills (79%), condom distribution (75%) and partner reduction (75%). They also emphasise education around first aid and HIV (86%) and sexually transmitted infections (STIs) (82%), which are areas less emphasised by CSOs and FBOs.

The most commonly reported prevention approaches reported above involve some form of individual behavioural adjustment or change. A significantly smaller proportion of organisations offer more specialised prevention-related services, such as clinical interventions. The organisations providing these more specialised services tend to be government institutions (see Figure 6).

Figure 6: Percentage of Organisations Offering Selected Prevention Services, by type



CSOs are less active in provision of the specialised services of VCT, PMTCT and PEP than they are in the more behaviourally oriented forms of prevention. FBOs are even less active in providing targeted interventions than are CSOs. Government services are the main providers of these services. However, there are some significant providers of specialised services that are *not* government institutions. In Grahamstown, for instance, more VCT tests are conducted by an NGO than in all of the government services combined.

Use of HIV-positive educators

CSOs, FBOs and government agencies use HIV-positive individuals as educators to varying degrees. Sixty-four percent of government institutions report using PWAs as educators, compared to 53% of CSOs and 36% of FBOs. Of those that do use PWAs, slightly more than half (51%) pay them for their work. This includes 61% of government agencies, 45% of CSOs and 40% of FBOs.

Some of the organisations that use HIV-positive educators expressed the view that they are effective in connecting with audiences, that their personal courage is motivating to people infected and affected by HIV/AIDS, and that the credibility which they bring gives their work greater impact, particularly among youth.

Condom distribution

Condom distribution is common among certain organisations involved with prevention work, but less common among others. Eighty-two percent of government institutions and 55% of CSOs distribute condoms, compared to 14% of FBOs.

Among organisations that distribute condoms 100% distribute male condoms, while a much smaller proportion distribute female condoms – 26% of government agencies and 29% of CSOs. There are no FBOs that distribute

female condoms. All organisations distributing female condoms do so free of charge. One hundred percent of government agencies and FBOs distribute male condoms free of charge, while 95% of CSOs do so. Female condoms are distributed by at least one organisation in each of the three sites.

Organisations noted that there are sometimes difficulties in ensuring a steady supply of male condoms for distribution. It was also noted that female condoms are not widely available in comparison with male condoms.

VCT

The survey identified 33 organisations in the three communities that offer VCT services. Forty-nine percent of these organisations are governmental, 45% are CSOs and 6% are FBOs.

Sixty-one percent of the organisations offering VCT use rapid test kits. Here, however, the difference between government and CSOs is marked – while 81% of government institutions use rapid tests, only 47% of CSOs use them. Given the many documented advantages of rapid test kits – including their practicality in resource-poor settings, their convenience, and the quickness with which they return reliable results – it is noteworthy that their use by CSOs is so limited.

Among organisations offering VCT, 15% do not have a private space or room in which to conduct counselling and testing. The lack of adequate facilities for VCT appears to be a bigger problem for CSOs than for government – 20% of CSOs offering VCT do not have appropriate facilities, compared to only 6% of government organisations.

Differences can also be noted in the profile of counsellors involved with VCT. Overall, 79% of organisations offering VCT use nurses or doctors as counsellors. A slightly greater proportion of organisations (82%) use volunteer and/or lay counsellors, while slightly fewer use PWAs (64%) and professional psychologists (45%). While government organisations tend to use nurses or doctors (88%), volunteer and lay counsellors (88%), and PWAs (75%) more often than CSOs (73%, 73%, and 60% respectively), they are less likely to use psychologists (31%) than are CSOs (60%).

Follow-up counselling is provided after the initial testing and counselling session by 79% of organisations offering VCT. Eighty-eight percent of organisations provide support group services and 79% refer HIV-positive individuals to other services in the community. There are no significant differences between the practices of government institutions and CSOs in these services, although CSOs are somewhat more likely than government agencies to refer HIV-positive clients to other community services (87% to 81%), while government agencies were somewhat more likely than CSOs to offer support groups (94% to 87%). The FBOs that provide VCT are less likely to offer these support services than are government and CSOs.

The survey collected information from organisations on the challenges they have encountered in providing VCT. Organisations noted issues such as the absence of broader support structures for individuals who test HIV-positive, the lack of a dedicated space to conduct counselling and, most of all, a shortage of staff qualified to provide counselling. This human resource challenge was identified by both CSOs and government organisations (hospitals, clinics).

PMTCT and PEP

Only a small proportion of organisations involved with prevention work provide PMTCT and PEP services. PMTCT is provided by 46% of governmental organisations and 21% of CSOs in the survey, while PEP is provided by 39% of governmental organisations and 5% of CSOs. No FBOs provide either PMTCT or PEP.

Government institutions providing PMTCT seem to be better equipped and better integrated into AIDS response structures than are CSOs. CSOs are less likely than government facilities to have private counselling space (75% vs 100%), to use rapid tests (38% vs 92%), to use nurses and doctors (50% vs 92%), to provide follow-up counselling (50% vs 92%), to provide support groups (63% vs 77%) and to provide formula feed to clients (13% vs 92%). While these discrepancies may not be surprising, given that PMTCT is predominantly associated with clinical (antenatal) settings, they are still of concern insofar as CSOs that are involved with PMTCT should ideally be providing similar levels of service as government.

The survey identified 13 organisations that provide post-exposure prophylactic treatment in the event of rape and/or sharp object injury. Eleven of these (85%) are governmental. Of these, 62% offer PEP after rape, while 85% offer it following sharp object injury. It is notable, and of potential concern, that only 54% of organisations offering PEP treatment monitor patient compliance with the treatment. This has implications in terms of drug compliance (i.e. ensuring that the ART short course is taken correctly), follow-up testing to confirm one's HIV status and, in the case of rape survivors, the medium and long-term emotional and psychological effects of violent crime.

Seventy-seven percent of organisations offering PEP report that they refer clients to other organisations. This suggests that PEP services are linked into broader HIV and/or post-trauma support networks.

Challenges and successes of prevention activity

Prevention activity is the most widespread area of AIDS response. As such, it is of interest to understand how organisations involved in such work perceive the impact and effectiveness of their activities, as well as the challenges they are seeking to address. Qualitative information captured in the survey addresses these questions further.

Many organisations identify lack of information, awareness and understanding about HIV in the community at large as a fundamental challenge to their prevention work. They also point to the continued existence of myths about HIV/AIDS – that condoms spread HIV, that white people can't contract HIV, that women are responsible for spreading HIV – as factors that work against prevention efforts. Ignorance and the perpetuation of myths are often linked, and both help to feed into stereotypes that

contribute to the stigmatisation of HIV-positive people – another factor cited by organisations as one of their major challenges. These, in turn, feed into a fear on the part of many people to go for testing and to disclose their positive status – another frustration noted by responding organisations.

The survey findings suggest that the prevention activities that predominate at community level are exactly those that aim to address the lack of understanding, misconceptions, stigmatisation, and fear of disclosure. These are outreach and awareness-oriented efforts aimed at increasing condom use, promoting abstinence or faithfulness, encouraging people to learn their status, and educating children and young people. In this respect, the forms of prevention work seem to flow organically from the challenges identified. However they are also the least specialised types of responses and therefore may be the easiest ones for community-level actors to undertake.

Organisations noted that it is difficult to know whether prevention efforts are actually effective – whether the condoms distributed are used, whether lessons taught to young people are applied, and so forth. Behaviour change is difficult to measure, and it is similarly difficult to draw clear lines of causality between specific interventions and HIV rates. This is a reality that is unlikely to change, yet it is important to acknowledge that organisations involved with prevention are struggling to some extent to understand what impact their work has. This challenge may also be linked to weaknesses in basic monitoring and evaluation (M&E) activities on the part of community organisations – an issue which is discussed in more detail later in the report.

The survey findings suggest that the most common prevention activities are also those that are the least specialised and that are aimed at large or general audiences (e.g. education, outreach, awareness-raising, promoting personal behaviour change, condom distribution). The least-common activities are specialised services, such as HIV testing, STI treatment, and provision of PEP, that are clinical interventions available to individuals to prevent HIV infection or transmission.

This has important implications for the way that AIDS responses are co-ordinated at community level. Ideally, organisations that pursue particular prevention approaches should be aware of and draw upon each other's work, refer clients to one another for needed services or materials, and share information and strategies. There need to be linkages between prevention and education efforts aimed at broad audiences, and the provision of more specialised or clinical services, such as VCT, that can assist individuals to learn their status. Issues relating to the coordination and integration of various types of activities are addressed in the discussion section following the presentation of findings.

Care and Support

As the AIDS epidemic in South Africa advances, a growing number of people are transitioning from the stage of asymptomatic HIV infection to the development of AIDS-related illnesses. Over time, the progression from HIV to AIDS affects people's ability to work outside the home, to perform domestic tasks and responsibilities, and to live and care for themselves independently. While anti-retroviral therapy can significantly prolong the healthy, productive life of an HIV-positive person, the relative inaccessibility of ART in South Africa means that many people who develop AIDS require palliative care, often in their homes, until their deaths. This places mounting demands upon the health care

system and families, most directly, but also upon communities as a whole as they grapple with the secondary impacts of HIV/AIDS on those affected by the epidemic.

Activities related to care and support of HIV-positive people and those affected by HIV/AIDS are widespread in South Africa. They are also becoming more critical as the number of sick people increases. However, in contrast with the high profile prevention and awareness campaigns, care and support activities are less visible. It is of great interest to better understand the scope and nature of care and support responses at community level, how they are being organised, and where the areas of emphasis are.

Care and support activities encompass an extensive range of initiatives, including support of orphans and vulnerable children, counselling and support groups, training and support of caregivers, spiritual and pastoral care, household assistance, nutrition support, and palliative/home-based care for the terminally ill. Organisations involved with care and support were asked to identify the kinds of services they provide and to comment on the challenges and successes they have encountered in this area of work.

Approaches to care and support

Seventy percent of CSOs, 55% of government institutions, and 44% of FBOs report involvement with care and support activities. Organisations offering care and support are present in all three sites, and most of the possible care and support services were reported to be available in each of the communities. This suggests that services are present across the three sites, although there is no way to gauge their visibility or accessibility to the general population on the basis of the available data.

Organisations were asked to indicate the type of care and support services they provide in the community from a list of 29 possible areas of activity. The most-provided services overall are emotional care (83%), counselling (83%), supporting PWAs (77%), promoting community care (76%), support groups (74%) and supporting families and caregivers (72%). CSOs are more active than government institutions in providing services in each of these areas.

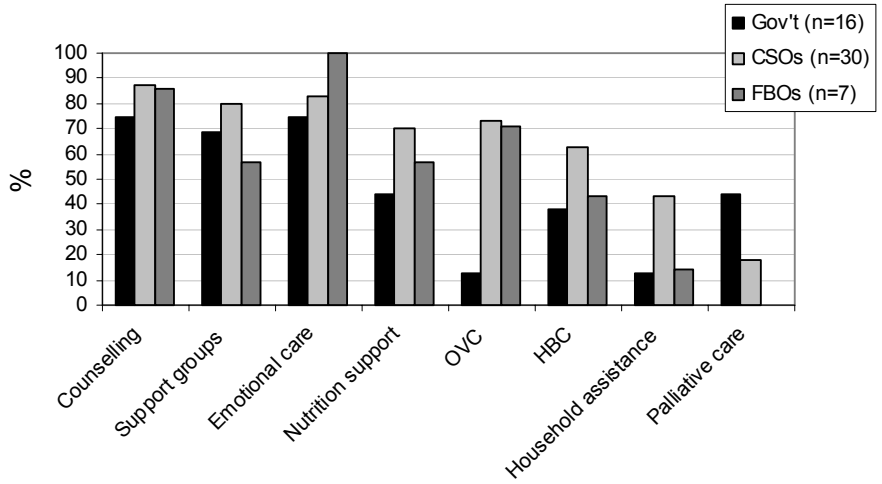
A smaller, but substantial proportion of organisations are involved in concrete service delivery in areas such as nutrition support (60%), support to orphans and vulnerable children (55%), home-based care for people sick with AIDS (53%), physical care (47%), including bed care, bathing and dressing, and income-generation projects (45%).

The least-provided services are assistance with shelter and placement (28%), legal services (25%), respite care (28%), palliative care (25%) and provision of financial assistance (19%).

As Figure 7 shows, differences in emphasis and level of activity can be noted between CSOs, FBOs and government institutions in a range of service areas. For example, a significantly greater proportion of CSOs than government bodies are active in providing

nutrition support (70% vs 44%), home-based care (63% vs 38%) and household assistance (43% vs 13%). An even more pronounced pattern is evident in relation to programmes supporting orphans and vulnerable children – while 73% of CSOs and 71% of FBOs have activity in this area, only 13% of government organisations in involved in work with OVC.

Figure 7: Organisations providing selected care and support services, by type



These findings suggest that in some of the key areas of AIDS care and support, CSOs and/or FBOs are the primary service providers for the community. These include direct 'frontline' caring functions in people's homes and support to vulnerable and affected populations (such as families and OVC). There are various possible reasons for this. In some instances, the services being provided are ones for which responsibility has not been clearly apportioned at government level. In the case of support to OVC, for example, no government agency has a clear mandate in terms of service provision – the portfolios of several ministries, including Child Welfare, Social Development and Home Affairs, touch upon OVC issues, but no one agency is clearly responsible for service delivery in this area.

CSOs may also be more active than government in terms of provision of care and support simply because they are located closer to community needs and are therefore more sensitive or responsive to these needs. In the absence of clear government mandates, CSOs may have stepped into the breach to provide needed services to the community.

It is important to note, however, that CSOs are not uniformly more active than government across the range of care and support activities. In more technical areas – such as the treatment of opportunistic infections/TB, immune system support (vitamins and others), palliative care, and medical consultations with PWAs – government organisations are more involved than CSOs (63%, 63%, 44% and 50%, compared to 33%, 30%, 18% and 30% respectively). Yet despite this the findings suggest that, on the whole, CSOs and FBOs are at the forefront of many care and support responses.

Challenges and successes in relation to care and support

Two main issues emerge in the survey in response to a question about challenges in the provision of care and support. The first is related to resource constraints – material, financial and human. Organisations report facing a lack of resources, including insufficient food parcels for distribution, a lack of funds to arrange transport for or to patients who need help, and inadequate facilities in which to conduct their work. Linked to this are human resource constraints. Organisations report that there is a high and unmet demand for caregivers and a need for more staff and volunteers.

A second broad area of concern focuses on interactions with families of people with AIDS. HIV/AIDS affects families in a number of ways, from additional financial strain and increased care demands and to bereavement and orphanhood. Care and support activities extend well beyond the needs of the HIV-positive person and often include complex dynamics involving the larger family. A number of organisations report that family members sometimes demonstrate negative attitudes, refuse to provide care for a family member with AIDS, or refuse to disclose a family member's status despite the clear need for care and support. Others noted instances where food parcels distributed to AIDS patients are exchanged for liquor or other goods, rather than consumed. Another organisation noted that AIDS affects the entire family unit, not only the person who is HIV-positive, and that it can be very difficult to meet the diverse needs of a household affected by HIV/AIDS. Still others note that families with HIV-positive members tend to become increasingly dependent on home-based care organisations with the passage of time.

Some organisations also noted challenges in interfacing with government and medical systems. Accessing social grants can often be problematic, according to some organisations surveyed, due either to long waits for the grant application to be approved or because of questions of eligibility (i.e. school pupils being underage). Another organisation noted that medical terminology is often not well understood, which can lead to confusion when completing certain applications for assistance.

Despite these challenges, organisations also point to successes in their care and support work – many of which suggest that the challenges identified are surmountable. A number of organisations noted that care and support services have a noticeable impact in terms of changing popular attitudes to HIV/AIDS, breaking down the notion that AIDS equals death, and reducing people's sense of pessimism and hopelessness.

Other organisations claim that they have found support for their work within the community, including volunteers, donations of money for food parcels and other services, and groups of committed caregivers who help shape the organisation's work by contributing insight on the changing needs within the community. This support has

allowed groups to provide food and clothing, to establish food gardens, to create peer support groups, and to provide a range of other services.

A number of organisations noted that work with families can bring about changed attitudes and heightened involvement. One organisation reported that providing 'emotional support' to families helps them to see HIV/AIDS in a different way and makes them more inclined to accept the HIV-positive family member. Others echoed this, noting that, given time, many families join support groups, are more open about supporting their HIV-positive family members, and more accepting of 'positive living.' This finding reaffirms the challenge inherent to work with families of HIV-positive individuals, but also suggests that the challenges can be overcome with time, engagement, and reference to other community initiatives.

Treatment

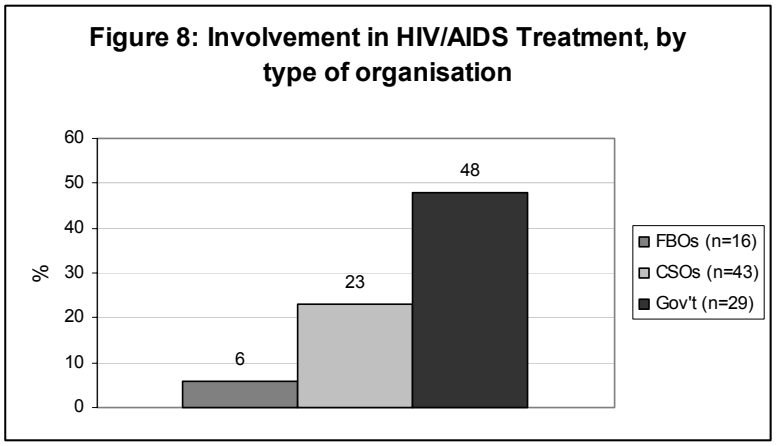
Treatment of HIV/AIDS encompasses a range of therapeutic services, including treatment of opportunistic infections, tuberculosis, and sexually transmitted infections and the provision of antiretroviral drugs. Beyond this clinical component, however, treatment can also be understood to include a range of management and support interventions such as treatment literacy, nutrition education and integrated management of HIV/AIDS, STIs and TB. These measures, aimed at maximising treatment adherence and efficacy, are essential complements to medical interventions. It is important to understand the extent to which these basic services are being provided and what types of organisations are providing which services.

Treatment may involve the actions of a single provider, but often involves the actions of different providers acting in concert. As the South African treatment programme expands, it is necessary to assess not only what services are provided by whom, but also the extent to which various treatment-related activities are co-ordinated and interlinked. There are important questions about integrated service provision in the area of treatment, particularly in regards to the provision of antiretroviral therapy, which demands the close co-ordination of a number of treatment and support agencies which may not have previously worked together.

Respondents in the study were asked to report on treatment-related activity – understood to include both clinical and non-clinical interventions – and to reflect upon successes and challenges in relation to this.

Organisations involved in treatment

Slightly less than one-third (28%) of the CSOs, FBOs and government institutions in the survey are involved with the treatment of HIV/AIDS. Of those organisations reporting involvement with treatment, 56% are governmental. Figure 8 shows the proportion of government organisations, CSOs and FBOs involved in treatment-related activities.



As the figure shows, almost half of the government agencies in the survey are involved in the provision of treatment-related goods or services. The government agencies most involved in treatment are local clinics and hospitals that provide treatment services directly to the public. However this category also includes government structures such as health districts, the Department of Correctional Services (DCS), the South African Police Services (SAPS), and the South African National Defence Force (SANDF).

Slightly less than one-quarter of CBOs are involved in providing treatment-related services. These structures tend to be hospices, home-based care organisations and support groups, but also include local health forums and groups that supply traditional medicines.

Relatively few FBOs report involvement in treatment.

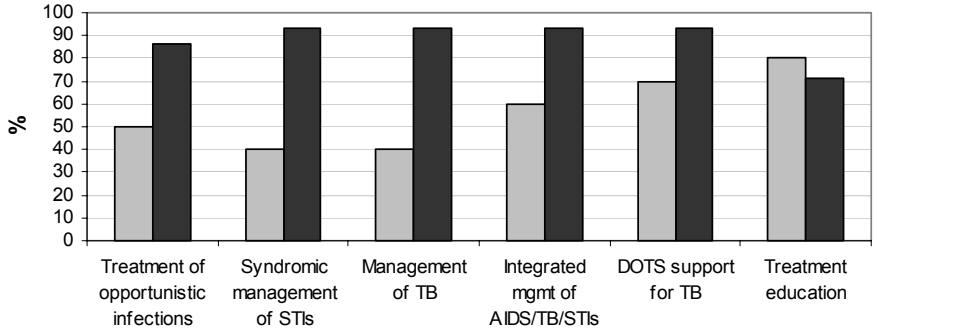
Nature of treatment services

Treatment-related activities include both clinical services, such as direct treatment of STIs, TB and opportunistic infections, and educational activities related to treatment literacy and approaches to integrated management of HIV/AIDS, TB and STIs. As Figure 9 shows, the treatment emphasis differs by type of organisation.

Government organisations are heavily involved in providing clinical services, such as treatment of opportunistic infections and management of TB and STIs. This finding is consistent with the dominant profile of such organisations – namely, clinics and hospitals. CSOs are significantly less involved in the direct provision of medical services.

CSO involvement with treatment focuses on treatment education and literacy (80%), DOTS (directly observed treatment short-course) support for TB (70%), and integrated management of HIV/AIDS, STIs and TB (60%).

Figure 9: Involvment of CSOs and Government Organisations in Treatment Activities



Involvement in the provision of ART is extremely low – only 8% of organisations involved with treatment report the provision of ART free or at low cost, while only 12% provide ART for patients able to pay (including through medical aid). As this survey was conducted during the early months of the government ART programme, it should be expected that this would have changed considerably, as Kelly and Mzizi (2005) have strongly suggested is the case in the Grahamstown site.

At the time when the survey was conducted, the government treatment programme was in its infancy and in the three sites there were no CSOs that were independently providing treatment (i.e. as key treatment service providers), as is the case, for instance, in certain locations in the Western Cape and the Eastern Cape where Medicins Sans Frontieres conducts independent treatment services. The involvement of 23% of CSOs in treatment programmes at this particular point in time therefore reflects various forms of support and participation, rather than a strong leading role. A very high proportion of CSOs in this category – 80% – report being involved with treatment education and literacy, for example.

Although further investigation is needed, the findings of this survey suggest that CSOs have become rapidly involved in treatment issues, given the relatively early stage of the treatment programme at which the study was conducted. This is not surprising, however, as organisations involved in providing direct services to people with AIDS, or involved in promoting VCT, often become involved in treatment programmes. Many such organisations have begun to work closely with the primary treatment providers – government – as the case study below describes.

Data collected from respondent organisations on the challenges and successes of treatment work support the finding that CSOs are playing an increasing role in supporting treatment roll-out, but are not in a position to act as independent treatment providers. Organisations report that they 'do not have drugs to give the people for free,' but can assist 'on how to take the drugs' for people who are enrolled in treatment programmes. A number of organisations cite challenges of treatment adherence – people not following-up at the specified intervals, people not taking their medication or not completing treatment cycles, and related issues such as poor nutrition. This is further evidence of the clear

need for treatment programmes to be accompanied by a battery of supplementary support activities. Finally, organisations also noted that as awareness of treatment grows, they are being approached by a growing number of people seeking access to treatment – an important, but unsurprising point given the enormous number of HIV-positive people in South Africa in need of treatment to strengthen their immune systems and control AIDS-related infections and illnesses.

CSOs Supporting Treatment Programmes[11]

The Grahamstown Hospice Association, like many hospice associations across South Africa, has been at the forefront of the provision of home-based care in the face of AIDS. The organisation has rapidly adapted from being a strongly volunteer-supported association which provided support to terminally ill cancer patients to becoming a leading agency in the provision of home-based care for people with AIDS.

As the support needs of treatment programmes have become more apparent, government health services are increasingly reliant on civil society organisations to address the need for such services. There are both opportunities and risks involved in this and these are highlighted in the case of the Grahamstown Hospice Association.

The association is contracted to the local hospital to provide home-based care services. The nature of the services provided falls well within the primary mandate of hospice. However, the recent introduction of ART has drawn hospice into a range of activities that extend its scope of services well beyond home-based care. They have had to conduct assessments to provide their home-based care patients with access to ART, work with families to support treatment adherence, provide treatment literacy training, support clients in obtaining necessary nutrition support, and work closely with the local ART task team, which is providing ART to approximately one quarter of hospice HIV/AIDS patients.

The availability of services often requires AIDS care and support organisations to begin linking and aligning with these services in ways that were not previously anticipated or budgeted for. The ART programme has added to the general burden of support and care placed on community organisations and has necessitated development and adaptation of most community HIV/AIDS programmes. There is a more pressing demand for referral links, for education programmes to incorporate treatment education, for ART adherence support groups and a range of other services. The cost of ART needs also to be assessed from the perspective of community organisations, and it is important to track how local support systems adapt to this new challenge.

Availability of treatment services

The data on treatment captured in the survey are limited to broad categories of services provided (reported on above), and it is therefore difficult to report in greater detail on the treatment services provided to people with AIDS or their reach. Moreover, these are rapidly evolving and a clear picture of service provision may be better apparent with the passage of time.

Drawing upon interviews with key respondents in the three sites, the following section looks at issues related to the provision of treatment services and their general availability across the communities.

[11] See Kelly & Mzizi, 2005

In the Grahamstown site there is a specialist HIV/AIDS clinic at the district hospital to which patients on ART and hospital patients are referred when specialist medical attention is required. Otherwise, treatment for opportunistic infections and monitoring is the responsibility of local clinics.

There are approximately 25 sites that provide ART in Gauteng Province, where Vosloorus is located. The closest service point for residents of Vosloorus is at the Natalspruit Hospital, which is located in the neighbouring township of Katlehong and which serves more than two million people in the surrounding region.

Obanjeni is served by a mobile clinic which provides rudimentary primary health care services. There is little available by way of services for people with AIDS in this area. This is especially notable, given that Obanjeni is located in one of the areas of the country with the highest HIV prevalence. A nearby clinic recorded an antenatal HIV prevalence rate of 42% in the 2002 antenatal survey.

It appears, therefore, that the reach of services is not necessarily contingent on the extent of the need for services, but rather on the general state of development of health services in the area and on the forms of planning that have taken place within health districts and municipalities. Arguably, the most important issue in determining the extent of service provision is the co-operation of different spheres of government and the relations between government action programmes which operate at different levels. Inter-governmental relations (IGR) appear to be the primary obstacle facing the effective financing and development of local services.[12]

Provision of health services is a provincial mandate[13] and municipalities provide services under contract to provincial health departments. In reality, the situation is in transition: municipalities are given a tranche of money to provide health services on behalf of provinces, but these funds usually prove to be insufficient, with the result that municipalities have to pay for services when funds run out. For this reason, health is often spoken of as a 'partly unfunded mandate.' For example, the Makana Municipality, where Grahamstown is located, claims to be owed significant funds by the province; the situation is noted by municipal officials as a significant problem for the municipality.

Communication and Education

Communication and education are intrinsic to all service provision activities in the AIDS field. It is difficult to imagine an AIDS-related activity that does not involve processes of communicative engagement with other service providers, with the public, or recipients of services. It is therefore of interest to understand the extent to which organisations see communications as a core function, embrace communication and education as part of what they do, and are able to meet communication and education demands.

The provision of communication and education requires access to already-developed materials – such as posters, guidelines, and pamphlets – or the ability to produce one's own materials on the basis of relevant information. It is therefore necessary to understand

[12] The work of Blauuw et al. (2004) provides penetrating commentary into the state of inter-governmental relations as they relate to the delivery of HIV/AIDS planning, programmes and services.

[13] Following the National Health Act of 2004

the availability and accessibility of existing materials for community organisations – and the frequency with which organisations choose to develop their own communications products. It is also important to understand whether available materials are tailored to and appropriate for the needs of organisations and the clients they serve.

If communities are to become increasingly engaged in AIDS responses, there is much to be done to align popular perceptions and understandings with the realities of the problems faced. Areas such as treatment literacy and PMTCT require an extension of public education focus beyond the well-serviced areas of awareness and prevention. It is necessary to know how well prepared organisations are for meeting these new challenges, including how well organised communication systems are and which communication approaches are favoured.

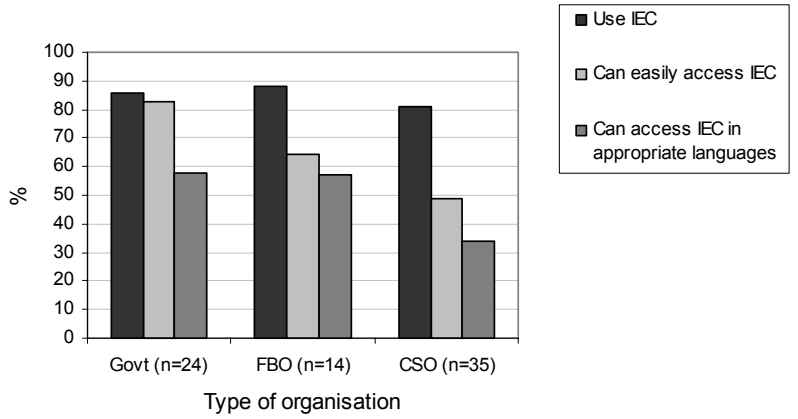
Accessibility and appropriateness of communication materials

Eighty-three per cent of the CSOs, FBOs and government institutions surveyed indicate that they use information, educational and communication (IEC) materials and/or interactive forms of communication in their work. This includes 83% of government organisations, 81% of CSOs, and 88% of FBOs.

Despite this high degree of emphasis on communications, many organisations experience constraints in accessing appropriate communications materials. Of those organisations using IEC, only 63% report being able to easily get the materials they need, and only 47% report being able to get them in appropriate languages.

These findings differ across organisational type (see Figure 10). Government bodies, for example, are more able to access needed materials than other types of organisations – 83% of government institutions report that they can access needed materials easily compared to 64% of FBOs and 49% of CSOs. This suggests that there may be bottlenecks to the distribution of existing materials outside government channels, or a lack of awareness on the part of other organisations about where and how to access communications materials. A number of organisations noted that it is difficult for them to get the materials they need easily (distribution points are far away), and in the quantities needed.

Figure 10: Use and accessibility of IEC materials, by organisational type



Posters, pamphlets and guidelines/manuals are the most commonly used educational materials – over 80% of organisations using IEC use these forms of information. Less common are video and audio cassettes, signs/billboards, and murals. Government bodies are slightly more likely than CSOs and FBOs to use video (63%, compared to 51% and 21% respectively), while FBOs are much less likely than government organisations and CSOs to use guidelines and manuals (43%, compared with 96% and 86% respectively) and posters (64%, compared with 92% and 91% respectively).

Accessing materials in appropriate languages appears to be a difficulty for organisations of all types. Only 58% of government organisations, 57% of FBOs and 35% of CSOs report that they can get materials that are suitable for their audience in terms of language. Some organisations noted that there is 'too much English, not enough African languages' and that 'language has been a problem.' This points to both an insufficient number of materials in various languages and inadequate distribution channels for materials that do exist. Among others, it raises the question of the need for a national or provincial-level IEC clearinghouse that could expedite the distribution of materials to local level.

In other instances, it appears that the content of the materials is problematic – for example, observations that the language used is sometimes too direct and therefore 'breaks' cultural norms for acceptability. Likewise, there seems to be an absence of information appropriate for certain audiences, such as young children and school pupils who require information presented in a simple format, or people with low levels of literacy.

These problems with access and language do not seem to be alleviated by the local production of materials. Only 21% of organisations that report difficulty in obtaining materials in appropriate languages produce their own IEC materials.

Use of communications approaches

The survey found that less interactive, straightforward informational approaches – such as the use of pamphlets and posters – are used more commonly than interactive techniques such as public events, door-to-door campaigns, and drama and theatre. Among interactive activities, a majority of organisations – 60% – identified 'events' as the most-favoured approach. Among government the proportion was even higher – 75%. This contrasts with the next most favoured approaches – drama/theatre (36% overall), street campaigns (36%), and songs (33%).

It is important to note the relatively heavy emphasis on 'events' as a vehicle for outreach and education about HIV/AIDS. Public events such as rallies, speeches, concerts, and sporting events are popular because they potentially reach large audiences and contribute to a sense of mobilisation and 'taking action.' However such events are often 'one-off' activities, or occur infrequently, rather than being embedded in a longer-term developmental process. They can also be expensive to organise. For this reason, the impact of events, relative to other

types of interventions, is questionable.

Use of HIV-positive educators

Overall, 54% of CSOs, FBOs and government agencies report using HIV-positive individuals as educators in their work. By organisational type, this includes 64% of government organisations, 53% of CSOs and 36% of FBOs.

Of the organisations using HIV-positive educators, roughly half (51%) pay them for their work, while in the other organisations the services are provided on a volunteer basis.

It is noteworthy that there is a significant difference between the proportion of organisations that pay volunteers (10%) and those that pay HIV-positive educators. Unfortunately, the survey data is limited here: the questionnaire did not probe the roles played by HIV-positive educators – or the frequency of their contributions – so it is difficult to interpret the implications of this finding with confidence. However, it would be important to investigate further the ways in which HIV-positive educators are used, the terms and conditions that apply to their work, and the manner in which they are identified, trained and recruited.

The fact that roughly half of the HIV-positive educators used by organisations in this study are providing an important service on a volunteer basis raises larger questions about the viability of this model going into the future. Can HIV-positive people be expected to continue acting as educators on a non-remunerated basis? Will the activities of HIV-positive educators become increasingly regulated and standardised as organisations develop and professionalise? Should donor bodies be supporting financially the work of HIV-positive educators among their recipient organisations?

Rights and Legal Assistance

The fields of law and human rights have a number of applications to the HIV/AIDS epidemic. As such, legal support and the protection of HIV-positive people's rights have emerged as a distinct element within the overall AIDS response in South Africa.

The South African Constitution protects citizens from discrimination on the basis of HIV status (not as a 'listed ground', but on the basis of 'other grounds') and guarantees HIV-positive people access to certain categories of social security. For example, HIV-positive people who have a major opportunistic infection and a CD4 count below 200 are eligible for disability grants. People caring for children with HIV may be eligible to receive care dependency grants. However, many HIV-positive people (or their caretakers) are either unaware of their legal rights and entitlements, or unable to exercise these rights in practice for a variety of reasons.

Qualified legal advice is often required to assist people to understand their rights and to assert these rights in the context of administrative or bureaucratic processes that can be inaccessible, cumbersome, and non-responsive. However it is not well understood how available or accessible such services are at community level, the extent to which legal advice centres or referral networks operate, and the involvement of qualified legal experts in providing advice.

Legal and rights-related responses to AIDS can include accessing social grants, legal support in criminal cases involving rape or abuse, and protection against discrimination (for example, unfair dismissal at the workplace and housing allocation discrimination). Organisations completing the survey were asked to comment on services rendered in the area of rights and legal assistance, their use of staff or volunteer lawyers, and the challenges and successes they have experienced in this area of work.

Provision of services related to rights and legal assistance

Of the 88 CSOs, FBOs and government institutions surveyed, 37 of them – or 42% – reported offering some form of legal assistance in relation to HIV/AIDS. This includes organisations working in each of the three sites.

Governmental organisations and CSOs are more or less equally involved in the provision of legal assistance – 52% and 49% respectively. Only 6% of FBOs report offering legal services.

Among those offering legal assistance, 100% report offering referral services and 78% provide support in reporting cases to the police. A smaller proportion of organisations work on advocacy for rights (46%) and the administration of legal aid clinics (24%).

Very few organisations – only 19% of those offering legal assistance – report having formally qualified legal staff within the organisation, while 22% report using volunteer lawyers. Government organisations are almost twice as likely to have legal staff than are CSOs (27% vs 14%), while CSOs are more than twice as likely as government organisations to use volunteer lawyers (29% vs 13%).

These findings suggest that HIV-related legal assistance programmes are generally available in the three communities, and that organisations rely heavily on referral systems to ensure that people are able to access legal assistance. The most commonly reported services – referral and assistance in reporting cases to the police – are not specialised services. However they are 'frontline' services in the sense that they enable people to access the more specialised assistance they require. The high proportion of government organisations and CSOs that offer support in reporting cases to the police – 87% and 71% respectively – suggests that law enforcement agencies are either inaccessible to local residents or difficult to engage with. The fact that residents require external assistance and guidance in accessing their legal rights to such a degree indicates that the law enforcement system does not actively support people's rights and is not structured in a way that facilitates uptake of these rights amongst the population that needs to exercise them.

When asked to identify challenges in this area of work, a number of organisations indicated that the biggest problem is that people are uninformed about their rights, particularly in rural areas. Linked to this, organisations themselves need a better basis in legal rights so that they are able to advise people correctly. A number of organisations referenced the challenges in dealing with the legal and law enforcement systems, noting that 'police take time to respond to cases' and regretting the 'non-implementation of the "nice" laws in the Constitution.'

Training, Human Resources and Capacity Building

AIDS response needs are rapidly evolving and for those working in the field there is a need to regularly update knowledge and understandings. Staff and volunteers of AIDS response organisations need access to training and ongoing education to develop their capacities and skills. In addition to this, because AIDS responses need to be expanded into new areas and upscaled, training is a high priority. It is therefore of interest to assess the way in which local entities are addressing their capacity building and human resource development needs.

Sustainable community-oriented AIDS responses require working environments which do not lead to burnout, which are rewarding personally and financially, and which are attached to future career prospects. It is important to assess the world of work for the range of people involved in AIDS programmes, including volunteers, part-time and full-time employees. Little is known about how many people are involved in AIDS-related work in the public sector, in civil society organisations, or as volunteers. It is important to understand trends in this area for reasons of planning and costing of future AIDS responses and the sustainability of such activities.

Although some progress is made in identifying trends, the survey questionnaire was not as penetrating as it might have been in uncovering human resource issues faced by organisations. This is clearly a very important area for further investigation, as it is readily apparent that AIDS response requires massive human resources, which need to be oriented, organised and developed to perform a rapidly expanding range of functions.

AIDS-related training

Sixty-two percent of government agencies, 63% of civil society organisations, and 31% of FBOs report that they provide some sort of AIDS-related training. This includes both in-house training for staff and volunteers, and training for external audiences. Training is available in all three communities and is primarily provided by government institutions and CSOs.

The most commonly reported types of training are related to behaviour change (88%), life skills (78%) and counselling (76%). Least common is training related to organisational development (36%), palliative care (32%), clinical/medical care (26%) and legal issues (24%). This mirrors findings in other sections of the survey which suggest that specialised services or expertise are concentrated in a smaller number of organisations, while general skills and approaches are promoted more broadly.

Photo: Raphael Centre

Of those organisations providing training, CSOs and government organisations seem to share responsibility for training relatively evenly, with FBOs involved to a significantly lesser extent. The exception is in the area of clinical and medical training where government organisations are far more active than CSOs (44%, compared to

19%). No FBOs offer clinical training.

In terms of training audiences, government training programmes tend to focus more on public sector employees, such as teachers (44%) and health care workers (56%), than do CSO trainings (22% and 33% respectively). CSO training, by contrast, tends to focus on more on community workers (67%) and volunteers (74%) than do government programmes (44% and 56% respectively). Traditional healers are the least likely to be the training focus of organisations with only 24% of organisations stating this as a focus.

Among the challenges cited by organisations in relation to training were low levels of uptake, shortages of training materials, problems finding reliable and qualified trainers, scheduling and time constraints, a lack of information about training opportunities, and a lack of monitoring of the extent to which trainees are applying and utilising what they have learned.

Extent of human resource commitment

Most organisations surveyed report having staff, including full or part-time staff working on HIV/AIDS. The use of volunteers was also very common: 70% of government institutions, 73% of CSOs and 88% of FBOs report using volunteers.

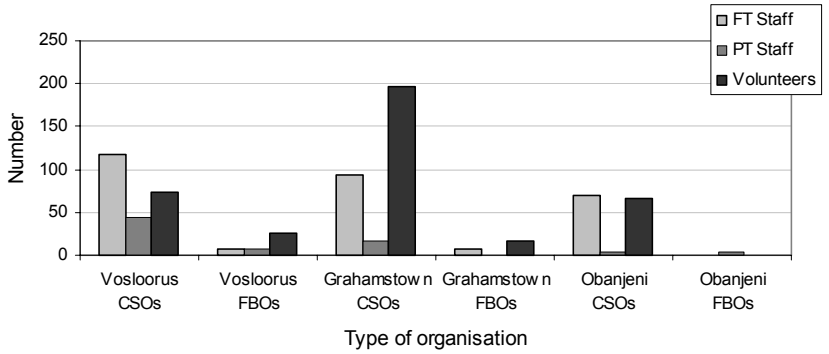
Among the CSOs and FBOs that completed the survey,[14] 371 staff are involved in HIV/AIDS activities. This includes 279 full-time and 65 part-time staff working in CSOs, and 16 full-time and 11 part-time staff working in FBOs.

The number of volunteers affiliated to these organisations – 378 individuals – slightly exceeds the number of total number of reported staff. Of these, 335 are affiliated to CSOs, while 43 are affiliated to FBOs.

According to the figures reported in the survey, there are approximately twice as many volunteers affiliated to CSOs and FBOs in Grahamstown (213) as there are in Vosloorus (99), and more than three times as many as in the Obanjeni area (66). The ratio of volunteers to total population in Obanjeni is approximately 1:150, in Grahamstown is approximately 1:290, and in Vosloorus is significantly higher at approximately 1:1500.

[14] Staff and volunteer data relating to government institutions are excluded here as large numbers of staff and volunteers are affiliated to clinics and hospitals, which were not comprehensively surveyed in the Vosloorus site.

Figure 11: CSO and FBO Human Resources, by site



The survey results show that CSOs use an average of eight volunteers (range: from 1 to 50) and FBOs use an average of five (range: from 1 to 15). Nearly two-thirds of CSOs (63%) use between one and five volunteers; only 12% of CSOs use more than 20 volunteers. Among FBOs, three-quarters use between one and five volunteers.

Despite the high usage of volunteers, only 10% of the organisations surveyed pay volunteers for their work.

Work conditions

Organisations were asked a series of questions relating to work conditions and staff working hours.

Fourteen per cent of organisations report having staff who work more than eight hours a day at least one time per week. CSOs and FBOs were more likely than government institutions to answer yes to this question – 16% and 25% respectively, compared to 7% of government institutions. Twenty-three percent of CSOs and 25% of FBOs, compared with 7% of government institutions, report that their staff work at least one weekend per month.

Nearly a quarter of CSOs (23%) report that staff are visited at home by clients once or more per month, compared to 13% of FBOs and 3% of government institutions.

These findings suggest that CSOs, and to a lesser extent, FBOs, work longer hours and seem to have a more fluid boundary between work and personal lives than do government workers. Staff of CSOs appear to be located closer to the communities they serve, and may as a result be less able to place limits on their involvement and accessibility beyond formal working hours. This has significant implications for issues of employee satisfaction, stress and burnout – all of which are factors that impinge upon the effectiveness and sustainability of an organisation's work. These questions are taken up in more detail in the discussion at the end of the report.

Challenges of human resource development

Although the quantitative findings described above help to illuminate key issues related to training, capacity building and human resources in AIDS-response organisations, a more

complete picture emerges when taking into account the short answers given by organisations when asked to describe the challenges of working with staff and volunteers.

In their responses most organisations touched upon one or more of the following issues: (1) the general shortage of staff and volunteers, which leads to stress and heavy workloads; (2) the need for more training and capacity building of staff and volunteers; and (3) the need for more financial support and/or incentives for both volunteers and staff, but particularly volunteers. A recurrent theme running throughout responses is a lack of needed finances.

Beyond these broad points, however, some specific challenges emerge. Staff and human resource shortages are not only constrained, but they are also exacerbated by the illness or death of staff members. Bereavement augments general levels of stress in the organisation and introduces additional emotional strain upon staff members. It also creates problems in terms of losses of skills and continuity within the organisation.

Problems with remuneration of staff and volunteers are acute and multi-faceted. Many organisations noted the need to give volunteers incentives: many of them are poor, some are prone to becoming sick, and in many cases are also required to arrange their own transport. Numerous organisations identified ‘transport’ as a core problem – volunteers often have to travel long distances from home to work. Organisations that don’t have their own means of transport rely upon volunteers to make their own way to visit clients in the community. In some sites this means that needs may go unmet as it is difficult to cover a large physical territory using volunteers who do not have transport or are required to pay for transport themselves. As one organisation put it, ‘People don’t want to work for free.’ Motivating, compensating and maintaining volunteers emerge as key challenges for organisations.

At the same time, however, it is evident that the volunteer element of AIDS response is broad-based, dedicated and continuing to expand. Organisations noted the growing number of people who are ‘willing to work voluntarily for the community.’ They describe them as committed, cooperative, and positive in attitude, despite the fact that they work under difficult circumstances.

Financial Management and Funding

The existence of functional financial management systems and the ability to attract or generate the finances needed to cover the cost of activities and staff time are crucial to the realisation of any organisation’s objectives. In many cases, the two issues are closely related. In the field of HIV/AIDS, where many activities are supported by government funding, foundation grants, or overseas donors, the question of financial systems – and general institutional capacity in relation to financial issues – takes on particular importance. Donors want to ensure that finances will be handled responsibly and transparently, and that appropriate records will be kept to document their use.

In many instances, a bank account and basic bookkeeping system are pre-requisites for the receipt of external funding and organisations lacking these may be technically ineligible for funding. This has particular implications for organisations at the grassroots level – especially for small or newly formed CBOs that may not be highly formalised in terms of systems, but that provide needed services to the local community. Organisations that do not receive external funding may find it difficult to grow and develop their

activities. They may find that they are limited by having to rely on the efforts of volunteers and compelled to operate on a 'shoe string' budget.

Bank accounts and accounting systems alone do not guarantee a steady or adequate flow of funding, of course, and resource mobilisation remains a key issue for many organisations working in AIDS response. Organisations must have the capacity to identify potential funding sources, to successfully access that funding, and to build a track record of programmatic performance that will ensure continued funding. In this respect, an organisation's human resource base, its access to information and useful networks, and its ability to design 'fundable' projects are key factors.

The survey collected basic data from organisations about the existence of bank accounts and bookkeeping systems, and about challenges and successes related to fundraising. These are reported below.

Financial systems

Bank accounts are fairly common among organisations in the survey, although a sizable percentage report operating without a bank account. Twenty-three percent of CSOs, 44% of FBOs and 67% of government institutions in the survey report not having bank accounts. Among government institutions, 48% do not have a financial manager or bookkeeper, compared to 26% of CSOs and 44% of FBOs.

The fact that approximately one-quarter of CSOs is operating without these basic financial management elements has implications for organisations' ability to attract and manage funds. It also points to challenges for capacity building and organisational growth. While it is perhaps less surprising that FBOs do not have these financial systems in place, the relatively high proportion of FBOs involved in AIDS response makes this fact somewhat worrying. It suggests that many FBOs will be required to depend upon local, non-monetarised/in-kind donations, rather than soliciting external support in the form of grants.

Funding and resource mobilisation

The survey found that government funding of community organisations is not particularly widespread. Forty percent of CSOs report receiving some government funding,[15] while there were no FBOs in the survey that reported receiving government funding.

The fact that only two-fifths of CSOs receive government funding is notable. The survey has found that CSOs are heavily involved with certain types of service delivery at community level – particularly in relation to care and support. Yet the relatively low proportion of CSOs receiving government funding suggests that they are not yet treated by government as a *formal* conduit for service delivery. This gives further weight to the view that CSOs are effectively occupying an otherwise vacant niche in terms of AIDS response – and that many of them are mobilising resources to support this work independent of government.

[15] The data does not allow us to draw any conclusions about whether the government funding that is received is intended to support AIDS-related activities, as in the case of non-AIDS specific organisations it may support other activities.

Organisations were asked to cite challenges they experience in relation to funding and resource mobilisation. Among those that answered, 23 organisations mentioned constraints in funding, 16 mentioned the need for specific resources related to their work (food parcels, office equipment, condoms, educational materials and/or transport), and eight mentioned shortages of volunteers, staff, caregivers or trainers (or an inability to pay them). These all reflect fundamental-level constraints to an organisation's ability to operate.

Most commonly reported were problems related to inadequate funding, a total absence of funding, or inconsistent funding flows. This suggests that resource constraints are widespread on the part of organisations involved in AIDS responses. A related challenge noted was the need to improve and develop organisations' fundraising skills and the ability to attract and locate resources.

Some organisations specifically cited difficulty in attracting funding to cover salaries for staff and volunteers. This is a critical issue if an organisation is to operate in a stable manner and to grow its operations over time. The absence of funding for salaries means that an organisation will struggle to operate on a full-time basis and will likely be forced to rely on unpaid volunteers, rather than on a stable staff complement that is able to think strategically about the organisation's work and undertake medium/long-term planning with the institution's interests in mind.

A number of organisations expressed a need to strengthen systems for financial control, management and distribution. This may reflect a lack of capacity on the part of funded organisations to comply with reporting and accountability requirements of donors.

Despite these challenges some organisations cited fundraising successes. These fell into to two main categories. First, some organisations cited successes in attracting funding, building and maintaining relationships with donors and securing repeat funding. Establishing an on-going funding relationship with a donor is an accomplishment, particularly for small organisations, as it requires time, a clearly developed programmatic focus, tangible outputs, and a relatively high degree of institutional capacity.

Second, a number of organisations reported that they are able cover the costs of their basic work, to provide small stipends to people involved in activities, and to purchase items/food parcels for clients. The data does not allow us to be certain whether this is a result of on-going donor funding, or a reflection of other types of support (such as donations) mobilised locally.

CSO funding profiles

Organisations were asked to identify their main funding sources, if any. Comparing responses from CSOs across sites, an interesting finding emerges.

In Vosloorus, CSOs receive funding almost exclusively from South African government sources – the national and provincial Departments of Health, the Department of Social Development and the J. Dumane Clinic (a conduit for government funding) – from private donations, and from private companies (Coca Cola and South African Breweries). One organisation also cited support from Uthingo Trust, a charity associated with the National Lottery. However government institutions were by far the most dominant sources of funding for CSOs.

In Grahamstown, by contrast, 16 different CSOs report receiving funding from non-South African, non-governmental sources, including a range of bilateral donors (e.g. DFID, USAID, AusAid, InterFund, and Danish, Swiss, German and Norwegian funding), private foundations and charities (e.g. Christian Aid, Mott Foundation, Solon Foundation, AVERT, the National Lottery), and private companies (e.g. Anglo Gold, South African Breweries, First National Bank and others).

In Obanjeni, with a much smaller sample size (n=8), two organisations received funding from sources other than government (ABSA, the Holy Cross Children's Trust and Breadline Africa).

These findings raise interesting questions about the distribution of types of funding across communities and access to non-governmental funding sources. Although this question clearly requires further investigation, some possible explanations can be advanced for the stark contrast in funding profiles of CSOs in Vosloorus and Grahamstown in particular.

First, it is known that the Ekurhuleni Municipality (of which Vosloorus is a part) is exceptionally active in supporting and promoting community-level AIDS response. This could account in part for the dominant role of government funding sources in Vosloorus, although it does not entirely explain the relative absence of other sources of funding. The notions of 'crowding in' and 'crowding out' – used in development economics literature to describe the behaviour of bi- and multilateral assistance agencies and other funders – may be of relevance here. Following this theory, after one funder has made a financial or programmatic commitment to a community or an area, other funders often tend to follow – structuring their interventions to build upon the work being funded by others (in the best case scenarios) or introducing projects that effectively duplicate or run in parallel to others (in less rosy scenarios). In other words, funding often follows 'established channels of assistance where networks already exist,' which effectively favours communities that are already well-populated with activity (OSAA, 2003).

The opposite of this 'crowding in' behaviour is 'crowding out,' where donors hesitate to invest in a particular area – perhaps because no others have paved the way, or as a result of other factors, such as perceived risk of low impact or a sense that an integrated response (in the case of Vosloorus, loosely overseen by municipal structures) is already underway. This can result in a self-perpetuating cycle where underserved areas remain underserved.

A second possible explanation has to do with the relative institutional capacities of CSOs in Vosloorus and Grahamstown to identify and secure sources of funding from non-governmental sources. It is possible that Grahamstown, as a smaller, better resourced and more prosperous community, has a higher density of organisations with the human resources and institutional know-how required to apply for, obtain, monitor and report on external sources of funding. This could also be linked to a greater degree of cohesiveness and communication amongst AIDS-response organisations in the community. It may also be that this finding points to a degree of 'crowding in' behaviour on the part of donors who perceive a critical mass of AIDS-related activity in Grahamstown and are keen to build upon existing work.

Monitoring, Evaluation and Research

Monitoring and evaluating programmes can help to evolve more systematic and effective responses to AIDS by, among other things, clarifying the demand, uptake and impact of various activities. When integrated into programme management and planning, M&E findings can greatly strengthen the effectiveness and reach of activities.

Funders are increasingly demanding to know the outcomes of programmes and require organisations to account for what has been achieved. At programme level this requires systematic monitoring of activities and outputs and the use of information management systems. It is important to assess the degree to which community-level programmes are aligned with accepted M&E practices and expectations, and to assess what may need to be done to develop capacities in this area. Towards this end a number of basic indicators of M&E practice were addressed in the survey.

The conduct of research amongst community organisations is also considered, although it is not expected that research would be amongst the organisational objectives of more than a small percent of community-level organisations.

Monitoring and evaluation practices

Sixty-five percent of CSOs, 44% of FBOs and 48% of government organisations monitor the number of clients using their services. This means that quite a sizeable percentage of these organisations do not keep records on the number of clients served. The most obvious implication of this is that it is difficult to quantify changing patterns of demand and use of services over time – a basic indicator for assessing an organisation's reach and a critical informational input for planning purposes.

A similar situation prevails with respect to the distribution of items such as educational materials and condoms. Among many organisations (35% of CSOs, 63% of government organisations, and 62% of FBOs), there does not appear to be routine monitoring of the quantities of materials in stock or distributed. This is perhaps not problematic, given that the supply of such commodities is erratic and materials are generally distributed as and when available. There is no strong motivation for keeping an inventory as there would be, for example, in the case of medicines in stock. Again, however, it means that there is an absence of reliable information about patterns of demand for various materials which would be useful for planning purposes.

Among CSOs, 74% monitor programme performance and deadlines, compared to 66% of government organisations and 38% of FBOs. This seems to be determined in part by the size of the organisation and the activities engaged in. Organisations which conduct regular and consistent activities – e.g. provision of VCT – tend to monitor number of clients seen and basic outcomes, but for organisations involved in advocacy, for example, monitoring categories are not as easy to establish.

Fifty-eight percent of CSOs, but only 25% of FBOs, have had their programme activities evaluated. This is not surprising and it is certainly not necessary for all organisations to be evaluated. Evaluation is generally seen as a funder-motivated activity and those organisations that have been evaluated appear to be those in receipt of donor funds, rather than smaller and locally or government-funded organisations.

The survey found that research is not a common activity amongst CSOs. Twenty-one percent of CSOs report undertaking research; a similar proportion of government institutions report involvement with research. When asked to describe the nature of the research, activities reported included basic needs assessments, canvassing of community perceptions, and service-oriented data gathering.

Respondent comments about successes and challenges in M&E work contribute to the somewhat 'patchy' picture of monitoring and evaluation as a poorly understood concept that, correspondingly, is de-prioritised. Among challenges cited, organisations noted a 'lack of cooperation' from clients and stakeholders when it comes to evaluating activities or monitoring numbers. Another organisation indicated difficulty in knowing what data is important to collect and in coordinating with people 'on the ground' who are in a position to gather the data.

Asked to cite successes, differing perceptions about the use of M&E emerge. Several organisations noted that M&E involved them receiving 'feedback' from community members. Others suggested that M&E is a way to self-assess strengths and weaknesses, to find out about 'user satisfaction,' and to know 'what you have done, to who and when.' One organisation linked M&E to the accreditation it received from national bodies.

In general, however, the survey findings point to a lack of capacity for conducting basic M&E activities and for establishing relevant foundations for an M&E system among community-level organisations. It seems that 'formal' M&E is still largely thought about as a funder requirement (which it is), and that simpler forms of M&E have not been promoted amongst smaller organisations where they are appropriate and can make a positive difference to the quality of work. This is taken up again in the discussion section, where the value of M&E as a development and management activity is addressed.

Coordination and Networking

Local HIV/AIDS organisations provide a range of services, but often do so in specific locations, individually, and on a relatively small scale. If their actions were co-ordinated, and linked up with government services, they could provide what would amount to a comprehensive and multi-sectoral HIV/AIDS programme with robust community participation. Co-ordination involves aligning parts like pieces in a puzzle. It seeks to avoid duplication, to identify gaps and needs, and to maximise coverage. It can also assist in planning for development and ultimately in developing better economies of scale.

Organisations responding to AIDS do not necessarily work exclusively in the AIDS field, and they may provide support services in a selective way. For example, a community legal resources centre may provide legal advice to people with HIV/AIDS, but this is only a small part of its work. Another example is a church health visitors' programme that assists people sick at home, including many with AIDS, but does not consider itself as

providing a specific AIDS-related service. The result of this is wide-ranging, but isolated and piecemeal activity that is not adequately connected to other efforts in a programmatic way.

In relation to this, much has been said of the need for partnerships between organisations working in the AIDS field, but there is little understanding of the forms of association that presently exist or of effective models for coordination that could be evolved. Contact between organisations may range from informal working relationships to formal memoranda of understanding, from loose referral networks to structured service delivery agreements. Given the rapid, but organic growth in the number and range of organisations involved in AIDS response, it is of great interest to assess the extent to which organisations in a single community work in cooperation – and indeed whether such a goal is seen as desirable.

There is a strong need to co-ordinate the development of initiatives, to create services which are integrated from a user perspective, and to facilitate the transformation of organic developments into systematic frameworks of action. Once we understand how AIDS response organisations are associated at community level, and identify the forms of co-ordination and integration which appear to be more successful, we are in a better position to promote and support those forms of association which may be conducive to sustainability, efficiency and sensitivity. It is important in developing support for local level responses to consider how organic growth can be effectively harnessed so that the constellation of local responses develops in a more co-ordinated and integrated way, without losing its dynamism and 'groundedness.'

The survey asked organisations whether they partner with other HIV/AIDS organisations and whether this association involves formal arrangements or memoranda of understanding on joint activity. Organisations were also asked to list the main organisations with which they have regular contact and to which they refer clients (or from which clients are referred).

The data captured in the survey itself is too limited to analyse issues of coordination and integration at a community level in any detail. However, qualitative interviews conducted with key informants in the three sites have been drawn upon in the following section to present a more comprehensive picture of the state of coordination and networking locally.

Extent of networking among types of organisations

Most organisations in the survey report networking or partnering with other HIV/AIDS organisations. As shown in Figure 12, 88% of CSOs, 83% of government bodies, and 50% of FBOs report networking with other organisations.

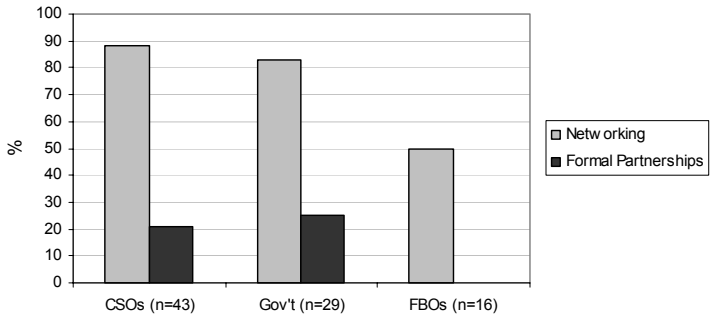
The proportion of organisations citing formal partnerships or work-related arrangements, however, is significantly lower. Figure 12 shows that 25% of government bodies and 21% of CSOs report formal partnerships. No FBOs report such partnerships.

It appears that some types of organisations are more inclined than others to co-ordinate with partners, perhaps because of the nature of the services they provide. For example, home-based care programmes require fairly intensive co-ordination with other service providers, but organisations that provide narrower or more defined services, such as laboratory services, may operate fairly independently of other organisations.

Challenges to networking

Organisations were asked to comment on the challenges they experience in networking with others. These can be divided roughly into four categories. The first area of difficulty relates to a lack of knowledge about other actors in the AIDS field. Some organisations noted that they don't know enough about other AIDS-related initiatives in the community, they don't know what other services are available for referral purposes, and aren't sure of the quality of the services provided by others.

Figure 12: Networking and Partnership Between Organisations, by type



A second commonly-mentioned challenge is around time – which in essence is about prioritisation. Several organisations noted that they don't have the time available to devote to networking, and that others appear to have the same problem. It was noted that people often apologise for not attending meetings that have been called for co-ordination purposes, and that it is difficult to prioritise co-ordination over other more pressing issues.

Third, several organisations noted problems linked to communication. These include a lack of follow-up from other groups, communication 'breakdowns,' incorrect information being conveyed, and very basic problems related to poor communication infrastructure – e.g. telephones not working.

The final area has to do with to poor relationships between organisations working in the same field. One organisation noted that 'competition within NGOs is very strong' and that there is a perception that some organisations actually seek to harm others. These negative political dynamics within the AIDS response sector are obviously harmful in that they undermine moves towards local co-ordination.

Extent of co-ordination at community level

In-depth interviews with key respondents in each site revealed that the extent of local AIDS response co-ordination differs significantly.

Local AIDS Councils (LAC) have emerged in many South African communities as forums through which leaders of key response sectors – FBOs, business, labour, health, education and others – meet to review local AIDS response activity, contribute to upgrading local response strategies, encourage sectoral and cluster coordination, and provide pro-active local leadership.

The formation of LACs is ongoing in all three sites, although only in Vosloorus is the Council functional. Co-ordination at ward level is a strong feature in Vosloorus.[16] Gauteng Province has assisted in establishing AIDS forums at the local level, comprised of all organisations working in the field. These are connected to local ward committees, headed by a councillor, that are intended to represent community development and support needs. The forums assist in taking stock of what areas of response are being covered and by whom, as well as identifying areas that remain unserviced. They are assisted and funded to a limited extent by provincial and municipal staff and resources.

In the other two sites the councils are in very early stages of development. In the Obanjeni site, the efforts to found a council appear to have been outsourced by the provincial government to an organisation which seems to have little understanding of the challenges faced and little experience in the HIV/AIDS field.

In Grahamstown a HAST (HIV/AIDS/STI/TB) committee meets on a monthly basis. It provides an opportunity for local organisations providing relevant services to discuss their work, share information, and co-ordinate planning around key health calendar events. The body has been functional for more than four years, but has steadily lost membership as the issues that require discussion have become more complex and simple monthly reports-back on activities less valuable. The need for joint planning in order to tackle numerous and complex service delivery issues has become apparent. What is required is a 'cluster approach' where organisations involved in treatment programmes, OVC support, PMTCT, and other areas, gather to discuss operational issues in a more in-depth way. Informal networks are emerging between organisations that have a shared focus.

In Grahamstown a service directory has been developed by local government, which covers social services, including HIV/AIDS services. But there has been no attempt to analyse the scope, extent or adequacy of services in meeting needs, prior to this research. The same is true of Obanjeni and Vosloorus.

To some extent, the fragmentation of response in all three communities is compounded by the fact that many community groups seem to develop with a focus on their own institutional needs as an independent entity, rather than on the needs of stakeholders and the activities of other organisations. While it is understandable that organisations focus on their own specific capacities and possibilities for responding to HIV/AIDS need, it appears that there is a need for greater attention to the 'big picture' at community level. The consequences of not doing this are evident in the Grahamstown site, for example, where two churches are independently pursuing major projects for responding to the orphan crisis without consultation and until recently without being aware of each other's intentions or activities.

[16] A ward in this context comprises a densely populated area of between 30 000 – 50 000 people.

Discussion

AIDS is an ecological crisis that affects all elements of a society and the way it functions, from patterns of individual interaction to family structures, productivity and economic development, the role of support networks, and the relationship between the state and the community.

As with any type of crisis, communities are mobilising in response to AIDS. Needs emerge and are identified, and individuals and groups take action to address them. Such mobilisation is happening at different speeds and is taking different forms, depending on the nature of the broader community, but seems to always involve an element of organic, grassroots activity on the part of individuals and social groupings who have been motivated to take action. These bottom-up responses usually occur simultaneously with other social responses originating from government, businesses, or outside actors such as development agencies. In some cases, these various vectors of activity intersect, and are even co-ordinated to an extent. But in many instances they evolve independently of one another, contributing to a rich but fragmented mosaic of local activity.

This study has sought to investigate and map forms of individual and collective action in response to HIV/AIDS in three South African communities. The findings of the survey, presented in detail in the previous sections, help to advance our understanding of 'who is doing what, where' and, to some extent, 'how.'

There is little point in trying to compare community responses outright: the communities themselves differ markedly from one another in terms of needs and resources, as well as their sizes, locations, and socio-economic profiles. Yet the data captured in the survey and the key informant interviews highlight a set of cross-cutting issues that appear to be germane to community-level responses everywhere. These merit further discussion and analysis. It is similarly of interest to interrogate the study findings with reference to the nascent literature on social capital and the potential this concept, in its various incarnations, might hold for better understanding and maximising community responses to HIV/AIDS.

From Organic to Systematic Response

Reflections on the evolution of AIDS response

The AIDS crisis is mobilising responses from a broad range of actors and the mobilisation itself has been gaining in pace, particularly over the last five years. While some of the key actors are public sector institutions – most notably, the Department of Health, clinics and hospitals, and social welfare agencies – there is a rich array of non-public activity that must be taken into account when considering community AIDS response.

Several key survey findings help to underscore the 'non-official' character of community AIDS response: there are more non-governmental than governmental actors involved with AIDS response in the three communities surveyed; the growth of non-governmental responses to AIDS has been rapid, particularly over the past five years; a large number of volunteers are affiliated to community AIDS response organisations and initiatives; and key care and support services are being spearheaded by community-based organisations.

This is not to suggest that CSOs are 'leading the way' in AIDS response (although in some areas they appear to be), nor that they are having a bigger impact than other actors, but rather that the contributions of community organisations and other social formations must be regarded as critical and integral elements of the societal mobilisations that are occurring nationwide.

The dynamism and centrality of CSO and FBO responses at community level require that we look more closely at both the sectoral areas in which they work and the manner in which they approach this work – i.e. how they access resources, build (or draw upon) expertise, utilise human resources, and interact with other actors.

The survey findings suggest that CSO/FBO contributions to AIDS are, by and large, still predominantly 'general' as opposed to 'specialised' in nature. Across the various sectors of response, activities most commonly reported by CSOs are also the ones that require the least technical expertise. Thus, in terms of prevention activity, the emphasis is on educational and outreach work on behavioural change, risk avoidance and life skills, rather than on the provision of VCT, PMTCT or PEP. Similar patterns can be detected elsewhere: care and support activity concentrates on emotional support, counselling, and supporting families and caregivers, rather than on more specialised functions such as palliative care; legal activities are limited primarily to referrals and support in interfacing with law enforcement structures; treatment-related activity is dominated by work on treatment literacy, as opposed to medical interventions.

Government institutions, by contrast, appear to dominate the more technical interventions and services, particularly medical ones, including provision of VCT, PMTCT, and PEP and the treatment of TB and STIs. They are notably less involved than CSOs, however, in playing the 'face to face' care and support roles – often in people's homes – for individuals and families affected by AIDS. CSO contributions are particularly evident in areas such as support to OVC, home-based care, and nutrition support. Much of the frontline psycho-social support provision appears to be occurring through community-based, rather than governmental structures.

These findings are not surprising, given that it is the state's mandate to provide health care services to the population and that CSOs, as a rule, are smaller and 'closer to the ground' than larger institutions. What is surprising, however, is the extent to which and speed with which CSOs (including faith-based groups) have already moved into areas that were either previously considered to be the monopoly of the state or private health care – e.g. the provision of VCT – or that are at the cutting edge of AIDS response more broadly. Treatment, for example, including the roll-out of ART, can be considered the newest and most high-profile area of response in South Africa, given the long build-up to a state-administered treatment plan and the enormous scale of the programme that is being attempted. Although CSOs are not yet independently administering treatment services,

they have bounded to the forefront in terms of supporting activities essential for the treatment programme to succeed: treatment education and literacy, support for family and caregivers, home-based care, and support to OVC, to name but a few.

In other words, CSOs are proving to respond more quickly and more agilely to evolving needs, perhaps because their location at community level allows them to see where action is required and even to anticipate, to some extent, the direction in which needs are shifting. This is not to say, however, that their contributions are more effective or that they are necessarily the best-qualified actors to be playing these roles. What it does suggest is that they are the best-positioned – and that there are obvious community-level needs, in absence of a more comprehensive and proactive public sector response, around which they are organising.

There is no 'road map' for CSOs involved in AIDS response and the survey suggests multiple areas where community organisations are challenged – where they reach the limits of their own knowledge and capacities and essentially 'improvise' solutions. On the frontline of a complex and rapidly evolving epidemic where best practices are not yet adequately defined, CSOs are being forced to handle wildly disparate challenges that pull them in multiple directions: assisting people to negotiate government grant systems; dealing with complex and contested dynamics involving the family members of AIDS patients; recruiting and managing qualified caregivers and other volunteers in resource-poor settings; fielding a growing number of treatment-related inquiries from the public; weighing conflicting guidance and opinions about issues ranging from nutrition to the safety of nevirapine; and figuring out how to finance their operations.

Given that many groups involved with AIDS response are not 'dedicated' AIDS organisations, but rather have incorporated an AIDS component alongside their core activity, it follows that there are numerous areas where they may require outside resources or assistance in the form of knowledge, expertise, or finances. For example, a church that initiates a care and support programme may not necessarily be trained in how best to support ART treatment regimes. Home-based care organisations may not have specialist knowledge about the requirements for accessing disability grants, an issue of critical importance to the people they support. Finally, many different types of organisations may struggle to find resources (funding and/or in-kind support) to support their activities.

These limitations in terms of knowledge or resources may lead groups to enter into contact with other organisations with whom they would probably not otherwise interact. Exhausting the capacities that reside inherently within their own groups, organisations may essentially be forced to build linkages with others in order to implement certain kinds of programmes, to improve the quality of their work, or to gain access to resources. The quality and density of these 'horizontal' linkages are of great interest, as they say much about the nature of collective response within a community. Applying Narayan's notions of 'bonding' and 'bridging' capital (1999), it may be that strong 'bonding capital' within various community groups is what leads them into AIDS response in the first place, but that the presence (or evolution) of 'bridging capital' between different types of groups is essential for a community response to become coherent and integrated.

Issues related to integration and coordination at community level are taken up again below in the section on AIDS governance.

Development and support needs

The survey captured information on the dozens of responses that are percolating up 'from below' and contributing to a vibrant, but disorganised societal mobilisation. If these organic responses are to become more orderly and more systematised – and if they are to be sustainable over time, given growing demand – the developmental and support needs of community organisations will need to be addressed.

The term 'organisational development' (OD) is often used loosely to refer to an array of normative and objective processes related to the overall evolution of an organisation. Organisations can 'professionalise' in terms of the sophistication of their approaches to work and the skill and expertise that they bring to bear on their activities. However, they can also grow in a very literal sense – in terms of staff complement, operating budgets, scope of activities, and programmatic reach. Both forms of development are fraught with challenges, and in many cases demand inputs or assistance from outside actors. While strong leadership can help to steer an organisation through successive developmental challenges, well-placed advice or support from without can be of crucial importance.

This section looks at four core OD challenges that seem to face community organisations in this study, with an eye to their practical implications for national and local government agencies, donor organisations, and other key stakeholders involved in scaling-up AIDS responses.

(1) Specialisation and expertise

One of the key findings of the study is that the greatest emphasis in AIDS responses at community level to date has been on general, non-specialised activities such as HIV awareness, life skills and behaviour change interventions, anti-discrimination and stigmatisation campaigns, and the promotion of care and support for individuals with AIDS. This is consistent with the notion of a groundswell of community activity around HIV/AIDS on the part of 'non-experts' – concerned, motivated individuals and groups wanting to 'do something' in response to an increasingly visible and destructive epidemic, but who are not specialists in public health, behaviour change communications, nutrition, or related fields.

Of course, not all AIDS response organisations are generalists – existing groups that work with abused children, the poor, or the terminally ill, for example, may find the transition into AIDS work fairly intuitive given their organisational histories and profiles and may be quicker to assume a more defined role. And some organisations new to AIDS do progress beyond general approaches and begin to carve out niches for themselves. Yet many groups, due to a lack of expertise, continue to focus upon outreach activities aimed at general audiences. These 'general' approaches, roughly speaking, focus more on awareness and information sharing than on the provision of specific services. There are two main implications to this.

First, a preponderance of 'general' responses means that similar types of activities are likely to be duplicated by multiple actors within a given community, without much attention being given to their overall reach or impact – or, indeed, the need for them. Questions of coordination and consistency of messages also arise in relation to this.

Second, the epidemic is progressing extremely quickly, and response needs are becoming both more acute and more complex. This suggests the need for a deepening and focusing specialised, targeted services that can complement more general approaches. General activities such as educational campaigns and outreach efforts are critical in terms of raising awareness and putting AIDS as an issue onto people's 'mental maps,' but they are unlikely to bring about behaviour change on their own and must be linked with a range of direct services to be effective.

Thus, the first issue relating to specialisation is the need to think about a shift in focus from general responses – what one might call 'unfocused mobilisation' – to the development of networks of organisations with clear areas of expertise or domains of service delivery. This has particular implications for donor agencies, government departments or other stakeholders that provide or promote capacity-building among community groups. It suggests a need to prioritise mechanisms for the transfer of knowledge and experience across and between organisations – either in the form of traditional training schemes, or perhaps through more innovative organisational mentoring relationships within sectoral 'clusters.' It also points to the importance of encouraging simple and practical M&E skills among community groups (addressed in further detail below), so that they can better identify gaps in activity, define their target audiences, and assess the adequacy of their own knowledge in a given area of work.

A second issue relating to specialisation was touched upon earlier – the fact that many organisations, regardless of the profile of their interventions or the complexity of the services they provide, are drawn into dimensions of AIDS response about which they have no specialist knowledge. This is clearly an issue both at the level of individual staff and volunteers – i.e. personnel need to be engaged in on-going training to ensure that their knowledge and understanding keeps pace with a fast-moving environment – and at the level of organisations as a whole which, in the course of providing particular services, bump up against the limits of their own knowledge of particular technical issues.

This again points to the need for 'segmentation' of AIDS response and clear linkages and referral networks between organisations with different areas of speciality. It may be more efficient, for example, for a home-based care or OVC organisation to partner with a group that offers legal advice and assistance than it is for them to try to guide clients through the application process for disability or care dependency grants themselves. This is related to larger issues of coordination and integration of services at community level which are taken up below.

(2) Evaluation of impact and strategic planning

In terms of organisational development, strategic planning and evaluation of impact are critical realms. Both are tools for advancing an organisation towards its larger objectives – the first by developing a road map that shows the way forward and the second by assessing progress in relation to goals. It is difficult, if not impossible for an organisation to plan for the future, to define more clearly its target audience, or to hone its activities if it does not have a sense of the scope and impact of its work.

The survey findings suggest that many AIDS response organisations struggle to understand the impact of their activities and, in planning their work, are not guided by a clear picture of the changing needs of the audience they intend to serve. This can be seen both in the relatively low proportion of organisations using basic M&E tools and in

the answers given to questions about organisational challenges. The fact that many organisations do not monitor the number of clients they serve, or track the quantities of materials they distribute, suggests that much community-level work is ad hoc and reactive, rather than strategically planned and implemented.

The survey results show that M&E is not being systematically developed at the local level, despite the fact that community organisations are proving to be among the most broad-based providers of AIDS-related services. Realisation of the hope that local organisations can provide relevant, locally supported and cost-effective interventions demands the development of appropriate, manageable and sustainable M&E systems in local organisations.

Unfortunately, there appears to be a significant shortfall of resources for the technical support required to develop even basic M&E capacity among community organisations. The value of M&E – and the techniques themselves – is not necessarily self-evident and on-going training and education is required to build awareness of and acknowledgement of the need for such activity at community level.

At local level the links with programme development and programme management need to be better established. There is surprisingly little reference in much of the recent HIV/AIDS evaluation literature to the place of formative evaluation in programme development, although there are some valuable resources put out by international support agencies aimed at programme level M&E. Formative evaluation is designed to improve programmes as they develop rather than to evaluate their results or impacts. It is generally less technical than outcome or impact evaluation (generically referred to as summative evaluation). The latter is usually employed at the end of programme cycles, to evaluate results, whereas formative evaluation (sometimes called process evaluation) is employed at strategic development points during the life of a programme and is primarily concerned with improving implementation.

The emphasis of funders is largely on summative evaluation, consistent with their concern to measure the achievements of programmes. Given the increasing tendency of funders to follow a ‘results-based’ disbursement approach (show the results to ensure further funding) it is increasingly important that service delivery organisations develop M&E frameworks and systems for this purpose. However, there is some risk that this need could supersede the need to adopt a programme development approach to M&E and more emphasis and development support appears to be placed on M&E that is oriented to funder needs, than M&E which is designed to build strong and effective local organisations.

Notably, it seems that government agencies at provincial and local level are as much in need of assistance as are CSOs and other community structures. This points to the need for an integrated approach to M&E capacity-building as part of a larger effort to evolve a more systematic and effective response to AIDS.

(3) Human resources

The scope of the AIDS epidemic in South Africa and elsewhere has prompted the emergence of ‘AIDS work’ as a veritable industry in and of itself. Medical professionals, development workers, private consultants, public health experts, social workers, caregivers, and massive numbers of volunteers are engaged in various aspects of AIDS

response. This small-scale study alone found that more than 1000 individuals in three communities are involved in some form of AIDS-related activity, with roughly equal numbers of full-time staff and community volunteers.

The effective and considered management of these human resources has enormous implications for the sustainability of AIDS response over time. Much AIDS-related work is emotionally draining and upsetting. It involves regular and close confrontations with illness, death, poverty, anger, despair, helplessness, and bereavement. The more intimately one becomes involved with the epidemic, the more evident its destructive impact upon families and communities. Many people involved with AIDS response may have close personal connections to HIV/AIDS as either infected or affected individuals. These and other factors can impact psychologically upon staff and volunteers and cannot be ignored. It is important to recognise that people working on AIDS at community level may need access to on-going support to help them manage the emotional stress of the work they are performing.

For AIDS response organisations to be stable and sustainable, working environments need to be professionally and personally satisfying for both employees and volunteers. While the survey findings point to high levels of community commitment and involvement in AIDS response, they also highlight the presence of the main 'ingredients' for burnout. The survey found that those affiliated with CSOs are more likely than employees of other organisations to work long hours, including weekends, and to be visited at home by clients. This suggests that the boundaries between work and personal life for many people in this situation are, at best, minimal. It is also evident that financial incentives are a concern for many people working on AIDS response – particularly volunteers. In a number of organisations, there are shortages of staff, sometimes linked to AIDS deaths or illnesses, which puts additional pressure on existing human resources. The combination of low pay, unclear job trajectories, and high levels of emotional stress can be problematic and over time can erode motivation.

The issue of volunteers merits separate attention. The survey revealed the large number of volunteers involved with AIDS response, and also highlighted the diversity of volunteer roles and input – from qualified lawyers who provide legal advice *pro bono* to unemployed community members who visit and care for sick people in their homes. Many volunteers do not only give of their time, but also of their own resources – covering the costs of transport, for example. While much more investigation remains to be done, the survey findings suggest that AIDS-related volunteering is already a large and complex realm – one that needs to be managed carefully if it is to be sustainable going into the future.

Although it is certainly not universally the case, volunteers are often taken for granted and their coordination, management and development is not always given the attention it deserves. In many sectors, assumptions are made that there is a more or less endless supply of volunteer labour that can be mobilised, depending on changing needs. Turnover tends to be high and investment in the professional/personal development and training of volunteers is low.

Already, however, volunteers are emerging as absolutely central to AIDS service delivery and must be regarded as a fundamental component of AIDS responses going forward. This may require a different approach to volunteer management than that which is presently used – one that looks at people's motivations for volunteering, their expectations of the volunteering experience, and ways to develop volunteers' skills and

capacities so that they can be centrally involved in the recruitment and training of new volunteers.

There is much discussion of the need to 'scale up' models of AIDS response across time and space, but it would be fallacious to assume that this can be done by simply expanding the number of volunteers to the required proportions. Volunteers need to be regarded as assets to nurture and grow, rather than expendable resources. Yet doing this requires taking a deliberate approach to volunteer management that is not commonly practiced in many organisations. Training and capacity-building in employee and volunteer management therefore emerges as another OD-related need for community organisations.

(4) Resource mobilisation

The survey findings show that resources are a chronic problem for many organisations working on AIDS response. The nature of the problem may vary – for some organisations funding flows are erratic and unpredictable, while for other organisations there are simply inadequate finances to conduct activities on the scale desired. These resource constraints affect both operational issues – provision of food parcels, distribution of materials, covering transport costs – and administrative ones (ability to pay salaries, overhead expenses such as telephone lines, and remuneration of volunteers).

Resource constraints link directly to organisational development issues. For an organisation to be financially solvent, with well-managed financial operations, it needs to be able to identify and attract funding or in-kind support; project and manage the flow of cash or donations on a regular basis; maintain accurate records and possibly have them audited; comply with relevant legislation, including the tax code; and develop in-house systems for financial monitoring and control. While these are achievable, they demand a degree of organisational thinking that is not always innate, particularly among newly established groups. They also require certain capacity in terms of bookkeeping, programme development, and outreach and promotion.

Large amounts of resources are being allocated by both governmental and non-governmental actors – national and international – in support of AIDS response. Thus, the challenges around resource mobilisation for local groups are less about an absence of resources as such, than about difficulty in gaining access to them. Available resources do not seem to be trickling down in adequate quantities to the grassroots level where they are needed to support vital activities. This is linked to, and compounded by, concerns about the 'absorptive capacity' of small-scale local organisations to receive and utilise outside funding to maximum effectiveness. Taken together, these elements contribute to a vicious circle that hinders the growth and development of AIDS response.

The fact that funding from above doesn't seem to penetrate down to local levels relates largely to existing patterns of donor support, including reporting requirements and administrative overheads generated by grants management procedures. For many donor agencies, it is simply not cost-effective to manage large numbers of individual small grants, given the time and resources required to oversee them. Donors therefore prefer to issue larger, longer-term grants to single recipients or consortia of organisations, or to 'outsource' grants management by providing block grants to umbrella organisations that can sub-contract to local organisations. Even in this case, however, reporting and financial accountability requirements still apply and many small community organisations

do not have the programmatic track record or financial systems in place to break into the 'funding game.'

As this suggests, there are glaring macro challenges around the funding framework for AIDS response. However from the perspective of individual organisations, there is an equally clear need to build capacity in resource mobilisation skills and financial management. This involves attention to processes such as project design and conceptualisation, development of promotional materials and funding proposals, and approaches to record-keeping (financial and activity-based). In many cases, this may also need to involve training in basic IT skills and assistance in identifying relevant resource agencies and sectoral networks.

It is important to note that not all community organisations are oriented on external grant funding. Some of them depend largely on in-kind donations that are gathered locally: donated food and clothing, access to transport, pre-paid telephone cards, even office space. Many of the challenges described apply to these groups as well – particularly those related to forward planning and management of supplies. Organisations must have in-house systems for projecting need and rationing available resources in order to provide regular services without disruption.

Striking a balance: individual organisational development versus 'system work'

As the previous section suggests, many AIDS-response organisations face very real and very concrete challenges to the evolution and sustainability of their work. It is therefore not surprising that, when asked to comment on the greatest problem(s) or challenge(s) they face, many organisations listed issues that pertain to their own day-to-day operations and survival.[17] As reported in the findings, organisations mentioned – in descending order - constraints in funding, the need for specific resources (food parcels, office equipment, condoms, educational materials and/or transport), and shortages of volunteers, staff, caregivers or trainers as their key challenges. These all reflect fundamental-level constraints to an organisation's ability to operate.

Moving away from challenges to 'survival' towards constraints to 'development,' a smaller number of organisations expressed challenges related to the need for more knowledge, information or training. This included in areas such as project management, counselling skills, ART, and PMTCT.

Only a handful of organisations expressed more complex challenges relating to their organisational role, vision, and interactions with others. These included: 'choosing projects and areas in which to work…it is difficult to choose one desperate need to be addressed over another,' 'communication with other organisations,' 'no follow-up from other organisations,' and 'lack of support systems and too much red tape.'

The distribution of answers that emerges through this simple clustering exercise seems to suggest that most organisations continue to focus the greatest attention on their own institutional needs, rather than on more strategic dimensions such as community-level

[17] Possibly due to the wording of the question ('What is the biggest problem or challenge your organization faces?'), which did not specify challenges related directly to HIV/AIDS activity, some organizations cited challenges that have to do more with the broader context in which they work, rather than with the organization itself. For example, common answers included the continued growth of the HIV/AIDS epidemic, the growing number of orphans, poverty, illiteracy, stigma and non-disclosure, people in denial, and reluctance to test.

coordination and networking. The resulting situation is paradoxical: although it is understandable that organisations focus most on their own immediate concerns – at the expense of integration and alignment with others – the development of systems and coordinating mechanisms can actually help organisations to resolve some of the issues that they find problematic and struggle with individually. On their own, many organisations may be unable to overcome the very practical challenges that hold back their development.

The findings of the study suggest that there needs to be more attention paid to the 'big picture' – to ways of coordinating and integrating the activities of organisations undertaking related work in the same communities. This will demand striking a careful balance between developing the capacities of individual organisations, each with their particular challenges and needs, and engaging in time-consuming and complex 'system work' that, if successful, can weave together individualised organic responses into more inter-linked structured ones.

AIDS Governance

The first part of the discussion has examined the implications of the survey findings at the organisational level, outlining the types of activity taking place, the challenges being faced, and the kind of support that may be required to develop the capacity of local organisations to mount an enhanced response.

The remainder of the section will look at macro-level issues relating to the 'governance' of AIDS. How can the vibrant organic growth that this survey has documented be harnessed in a way that allows it to retain its dynamism, while growing in a more co-ordinated and integrated way? Whose responsibility is it to facilitate such a process? Are there any existing models that shed light on these issues?

We look first at concepts of local coordination and integration – what it means and why it is needed – before turning to a discussion of some of the challenges that seem to be impeding the emergence of more co-ordinated and integrated responses. We conclude by touching upon some issues that relate to the nature of partnerships between governmental and non-governmental actors in relation to AIDS response. Throughout, we are concerned with the question of how disparate groups – each with their own constituencies, approaches, and priorities – can bridge their dissimilarities and link with one another around a concern common to the community at large.

The need for local coordination and integration

This report has presented a picture of active, yet fragmented community-level responses to AIDS. Local organisations are providing vital services to affected individuals and families, but often on a small scale, and are rarely 'joined up' with other such initiatives, or with government services. If these various elements were to be integrated with one another, even loosely, together they would come much closer to providing a comprehensive response to AIDS grounded in the fabric of the community itself. Coordination would also serve to increase the performance and efficiency of service provision, reduce unintentional duplication of efforts, minimise competition between organisations and perhaps contribute to the better sharing of limited resources.

There are several core concepts, or building blocks, that are essential to any discussion about integration. Integration is an extension of coordination. It is about getting pieces to come together into a coherent whole, such that users find the resulting system of functions and services coherent and easy to navigate. It may be likened to a building with many doors: an integrated system requires that, irrespective of one's point of access, the system operates as an interconnected network in which all new arrivals traverse a similar pathway.

The related concept of functional integration describes integration which occurs at the points of health service delivery, and which is oriented primarily on utility for the service user. The classic example of a functionally integrated community centre, for example, would see primary health care services, social welfare administrators, and a legal advice desk all located in a common space.

Functional integration usually involves the alignment of key services, the establishment of referral networks, and the development of consistency in norms and standards of practice across functionally related services.

Alignment is a term often used in policy development and planning. It refers to efforts made to ensure that policies and practices conceived by different agencies or actors are consistent with one another, and are properly sequenced. In relation to AIDS response, alignment refers to the development of complementary and supplementary services as a result of planning and co-operation between service providers. Services might be said to align when advice or training provided by one organisation adds to or extends the training provided by another organisation, or where an information system in a VCT organisation is consistent with a district M&E system. That is, the services offered or systems used are compatible, and do not duplicate one another.

Another essential feature of integrated service systems is the development of co-ordinated referral networks which allow multiple points of access for users (Toomey, n.d.). Referral follow-up is a well-known problem for local service organisations: users get lost in the system. For example, people who have had VCT and are referred to other service organisations often do not reach their destinations and are only picked up by the system of care and support when they become desperately ill. Reasons for this are legion, but it is generally accepted that better-developed referral and follow-up systems can address such problems.

When users of services are referred to services such that the referral agency is expecting them, the procedures involved for gaining access to services are familiar to them, and the advice offered to them is consistent, their motivation to use those services and their compliance with the requirements of those services is generally much better. The need for such a system is particularly critical in a dynamic environment such as the one described

in this report: service provision is scaling-up rapidly and more and more different types of actors are becoming involved, yet the standards and best practice for these services are still being identified and formulated. Organisations do not necessarily know one another, and are not always aware of the services available in their own locality. They also often follow different norms and standards of practice, for example in the basic approaches used in counselling and HIV testing.

These aspects of integration do not, and will not, simply emerge on their own – particularly in a rapidly changing and fluid field such as AIDS response where so many different types of actors are involved in service provision. Integration requires goal setting, planning, and a fundamental commitment to partnership on the part of disparate groups focusing on a particular aspect of a complex and multi-faceted epidemic. As the following section shows, some signs of movement towards functional integration are evident in the three sites, but to greatly varying degrees.

The evidence on functional integration

A number of efforts aimed at building functional integration were observed within the three sites, but on the whole, none of the sites can be said to have integrated service provision in relation to HIV/AIDS.

In both Vosloorus and Grahamstown there are versions of multi-service centres where users of social and health services can go for 'one-stop' assistance – for example, for health services, as well as family planning assistance and legal advice. However, these are not specifically oriented around the needs of people with AIDS. Thus, while there are local precedents for functionally integrated service provision, these have not yet been adapted and upgraded to meet the growing needs of HIV-positive local residents and their families.

The Obanjeni site, by contrast, is so undeveloped in terms of services and infrastructure that there is little to integrate. In terms of health care services, for example, the nearest clinic is a few kilometres away and the area is primarily serviced by a mobile clinic. The scarcity of resources in rural areas makes integration more difficult. People live at a distance from one another and although there are two areas where habitation is more concentrated, access remains difficult. There are no tarred roads in the area and some of the roads are in poor condition. Irregular formal and informal taxi services transport people to towns at certain times of day, but internal transport tends to be by private vehicle or foot. This means that access to services, especially for those who may be sick or frail, is problematic. This makes functional integration particularly challenging.

In other countries where rural populations have been strongly affected by AIDS, capacity development of community-level response and support systems have been turned to as an approach for overcoming the problem of service delivery to relatively sparsely populated rural areas. Unfortunately there has been limited development of this nature in the Obanjeni area and community-based care and support systems are not in clear evidence, although there have been some isolated attempts at developing care worker systems around clinics in the municipal area.

In terms of alignment of services, there is little evidence of such development in any of the three sites. In Grahamstown, for example, there is little involvement of either the National Association of People With AIDS (NAPWA) or the local VCT centre with the

government antiretroviral programme. There are clear ways in which these services complement each other, and there is no strong opposition to co-operation, but it is a development need which remains unaddressed because the organisations involved are preoccupied with more basic or fundamental operational issues.

The lack of adequately developed referral processes and shared information systems has been identified as a problem by local organisations, but there is little evidence of the problem being addressed. The development of improved referral processes and information sharing would require better co-ordination structures than currently exist in any of the sites. The Vosloorus site has developed a closely knit system of referral at ward level, and perhaps focus on smaller and more proximal referral systems is the most effective way to develop such systems. However, referral systems to hospitals, social workers, and higher-level service tiers for more specialised assistance would not be addressed through very localised systems. Nonetheless, beginning with the development of referral procedures between facilities seems like a promising way to proceed.

Although community organisations in Vosloorus and Grahamstown expressed the need for shared norms and standards of practice in relation to AIDS response, there appears to be little formal or consistent activity around developing inter-organisational operating standards, norms and procedures. The formation of inter-organisational committees concerned with particular areas of service (e.g. home-based care, OVC etc.) around which there can be functional integration, rationalisation of responses, and concentration of efforts would be of great value and a long-term source of support. However, engaging in the inter-organisation 'system work' required to evolve this coordination appears to have taken a backseat to individual organisational development needs. Ultimately, however, sustainability of local responses at the scale in evidence will require investment by even the small organisations in inter-organisation work which can tackle the problems shared by all, and then allow for greater focus on the unique challenges faced by individual organisations.

Other contexts, however, provide compelling models to be considered and possibly emulated. In KwaZulu-Natal, the Children in Distress (CINDI) network of organisations[18] promotes greater integration of activities among the multiple organisations who work in the interests of children affected by HIV/AIDS. Comprised of more than 100 NGOs, CBOs, government departments and concerned individuals, CINDI has created a multi-sectoral approach to networking which involves collaboration, capacity building, coordination of research, joint resource mobilisation, and advocacy work. Membership is free of charge and annually renewable. Decisions are made democratically, and the network welcomes the contributions of all member organisations, regardless of size. One of the guiding principles of CINDI is that its members 'complete one another' rather than 'competing with one another.' CINDI members participate in working groups formed around specific issues, and also are affiliated to thematic 'clusters' such as health care and home-based care, schools and youth development, and psychosocial support. The network provides a forum where issues of concern to member organisations, such as the payment of stipends to volunteers, can be addressed collectively.

[18] http://www.cindi.org.za

Challenges to integration

The challenges to integration and coordination locally are numerous. This report has focused on some of the challenges that exist from the side of the community: resource and capacity constraints, absence of strategic plans and assessment of impact/demand, lack of information about the work of other actors, failure to prioritise networking, and in some cases, a sense of competition or 'territorialness' in relation to other groups. However it is critical to look at two additional challenges that pertain most directly to government: the failure of many municipalities' integrated development plans (IDPs) to integrate AIDS responses at local level, and difficulties in inter-governmental relations.

(1) Lack of an integrated approach

Following the Municipal Systems Act of 2000, all municipalities must undertake an integrated development planning process to produce strategic development plans – known as integrated development plans – for a five-year period. An IDP must be produced within the first 12 months of a municipal council's elected term and represents the principal strategic planning instrument which guides and informs all planning, budgeting, management, and decision-making in a municipality. While local governments are responsible for leading the IDP development and review process, they are to do so in a way that both encourages and facilitates public participation. IDPs are intended to reflect community needs and priorities and the developmental plans of action which they contain should have the support and buy-in of various stakeholders, including community groups and the private sector.

IDPs are one of the key ways in which municipalities can integrate HIV/AIDS response into local governance plans and practices. However, the HIV/AIDS components of the IDPs in all three municipalities suggest that they are often not based on adequate situational analyses of the unique context of HIV/AIDS within the municipality. Moreover, HIV/AIDS responses on the part of NGOs and other local actors are proliferating so rapidly that IDPs tend to lose alignment with HIV/AIDS development priorities which may be addressed by non-governmental organisations and provincial government agencies. There is little evidence that an integrated approach to HIV/AIDS response planning is being adopted on a wide-scale and much local government effort remains sector-bound.

Local government responses in all three sites are occurring in the absence of an institutional framework for multi-sectoral responses, although plans are afoot in the Ekurhuleni Municipality, which governs Vosloorus,[19] to develop such a framework. Local government in Grahamstown and Obanjeni has not responded to HIV/AIDS in an integrated way and HIV/AIDS response is not yet prioritised as a municipal mandate. There are many reasons for this, including municipal backlogs, restructuring, and lack of personnel and capacity. There has also been little guidance and support for municipalities in developing the HIV/AIDS component of their IDPs.

Success stories from other municipalities show that local government can play an important role in integrating services and making HIV/AIDS part of broader community

[19] This has been reviewed in Kelly & Marrengane, 2004.

development planning.[20] Local governments that have adopted a municipal partnership strategy have been able to attract significant funding and support for HIV/AIDS response. Strong local government action has played a leading role in developing multi-partner co-operation and systematisation of community AIDS response. Unfortunately this is not the case in any of the municipalities under study, although some promising developments in this direction have been occurring in Ekurhuleni.

(2) Intergovernmental relations

South Africa's provinces finance nine areas of HIV/AIDS service provision, including VCT, PMTCT, PEP, ART and nutrition programmes, through the mechanism of conditional grants,[21] and are tasked with ensuring that the allocated monies are spent appropriately in developing and providing such services. These funds, which are granted by the National Treasury to the Directorate of HIV/AIDS/STI/TB (the 'AIDS Directorate') in each province, constitute the primary source of provincial AIDS funding.

The provincial AIDS Directorates are therefore tasked with spending money, allocated via conditional grants, on services that are provided by other departments, such as primary health care clinics or hospitals. It is a significant problem that the provincial AIDS Directorates do not have the authority or influence, nor the human resources, to plan and direct implementation within the context of services provided by other departments. The solution in the Eastern Cape, for example, has been to use the funds to provide particular supplies and services (e.g. laboratory costs for testing) and to pay for training for primary health staff in operations around VCT. Still, however, they do not have the authority to manage how services are provided. They have the power to fund local AIDS organisations, but have few mechanisms at their disposal to assist the organisation to work within an integrated framework with other service providers.

The key problem here is inter-governmental relations. Structures for inter-governmental co-operation have been established at provincial level, but they appear to be understaffed and have clearly not resolved some of the key problems of the 'split functions of government.' These refer to the fact that key services, such as VCT, require the co-operation of multiple sectors of government – sometimes at different levels of decentralisation. The frameworks for such co-operation have not been adequately worked out either on the ground or at higher levels.[22]

Some of the most critical issues facing organisations working at local level need to be resolved through better co-operation between government departments. Examples include:

- The need for closer co-operation between health officials and department of social development officials in addressing the confusion which abounds around

[20] See Kelly and Marrengane (2004) for an overview of HIV/AIDS activities in South Africa's nine metropolitan municipalities.

[21] A conditional grant is a grant which is tied to specific area of services and hence spending; e.g. VCT. There is not discretion to spend it on anything else. The equitable share budget on the other hand is money that passes from national to provincial spheres which is not tied to conditions, and provinces have discretion to spend it as they please.

[22] Many such problems are identified in Blauuw et al. (2004).

continued access to grants for patients undergoing ART when their CD4 counts go above 200;

- More efficient and dependable systems of financial disbursement between provincial departments and local facilities;
- Ongoing training support and upgrading for local trainees in many areas of service delivery;
- Consultation on key decisions that have major implications at local level, but which are implemented without consultation with local authorities; and
- Development of monitoring systems that allow satisfactory accounting by local authorities to avoid disbursement delays because of reporting inadequacies in a context where expectations have not been made clear.

These problems, and many others, show at local government level to varying degrees. Where the province is very active at local level, as is the case in Vosloorus, strong guidance and better organised systems are being put in place. Where this is not the case, such as in Grahamstown and Obanjeni, there appear to be more marked problems of inter-governmental misalignment between provincial and local spheres. These problems seem to be multiplied when they become problems of local civil society organisations, which appear not to have much understanding of the mechanisms of government and government funding, or knowledge of channels of intervention. They are often mystified and dumbfounded by the problems which they are confronted with in being supported by or co-operating with government.

It would appear that there is much work to be done in rationalising systems of inter-governmental co-operation. Intergovernmental structures are certainly not lacking in number (Blauuw *et al*, 2004), but these committees and standing structures of government appear to be lacking vitality and decision-making ability. What is needed are systems of fast-tracking and troubleshooting through the maze of inter-governmental committees and systems. This is why it seems important, in all spheres of government, that multi-sectoral responses to AIDS be directed from the offices of the political or administrative heads of government – for example, the premier's office, the mayor's office or the city manager's office.

The AIDS epidemic and its response needs at local level are developing at a pace which far outstrips the capacity of government at all levels to respond rapidly and decisively to new challenges and needs. This is all the more the case in a context where there is already a significant backlog in other areas of delivery, such as basic services and infrastructure. These 'hidden' problems of governance, rather than the more obvious problems of leaderships are arguably the

biggest problems facing AIDS response in South Africa, and it seems to be an area that has not been systematically analysed and understood.

An Evolving Relationship

As the AIDS epidemic in South Africa intensifies and grassroots activities related to HIV/AIDS burgeon in communities across South Africa, questions of effective AIDS governance are taking on ever greater importance. One dimension of this issue is the nature of the relationship between governmental and non-governmental actors. Will it be one of complementarity, where AIDS governance is strengthened by the active synergy of state and civil society actors? Or will it lean rather towards a situation of substitution, where the state is unable to cope with the scale and severity of the AIDS epidemic and large areas of response are taken over by community-led initiatives?

There is little question that local-level community activity can never be a replacement for large scale, national-level responses to the epidemic, even as they appear to be playing the leading role in certain areas of 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 the fact that they emerge from and reflect local conditions. As the findings of this study have shown, community-led AIDS initiatives are uniquely positioned to identify, highlight and respond to changing needs. As part of mutually supporting partnerships with governmental and other actors, they can act as a logical complement to large-scale top-down strategies.

Multi-sectoral partnerships do exist and are possible to nurture. 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 CBO and NGO activity, by publicly reiterating government commitment to and support of people living with HIV/AIDS, and by mobilising financial support for community institutions in the fight against AIDS (Jamil, 2004). On a much smaller scale, localised networks, such as CINDI in KwaZulu-Natal (discussed above), demonstrate that it is possible for civic and state entities to work together in partnership in a way that enhances overall effectiveness of individual efforts.

Much remains to be understood about how community organisations can be best supported in developing their capacity. Debates over the need to 'scale up' successful local models are important, but caution must be exercised in ensuring that organisations oriented on localised responses do not become fatally over-extended as part of efforts to increase reach, coverage and impact of activities. The findings of this study suggest that one of the best ways to enhance the impact of community AIDS response organisations may be to focus upon partnership building at the local level – to enhance coordination between various actors, to strengthen referral networks and information sharing, and to emphasise the integration of various AIDS-related services. Strengthening ties between a diversity of groups and organisations locally may be one of best ways to facilitate collective action in relation to this enormous shared challenge.

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