Community Perspectives on Systems Effects of HIV/AIDS Funding in South Africa

Written by

Kevin Kelly, Karen Birdsall, Patience Tshose, Prerna Banati, Daniel Low-Beer

Research team

Kevin Kelly, Karen Birdsall, Patience Tshose,

Vicki Doesebs, Thembakazi Mantshule, Zinhle Nkosi, Andile Tobi

Centre for AIDS Development, Research and Evaluation (CADRE)

Braamfontein Centre, 23 Jorissen Street
Braamfontein, Johannesburg
Tel: +27 11 339 2611

7 Prince Alfred Street
Grahamstown
Tel: +27 46 603 8553

Contact: Kevin Kelly • k.kelly@ru.ac.za

Acknowledgements

In each of the three communities there were groups and individuals who facilitated contacts with local organisations and key informants. We would like to express our appreciation and acknowledge their contribution to this research.

We also acknowledge the contribution of those individuals and organisations that participated in the surveys and interviews.

Disclaimer

This report does not purport to represent the views of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Executive Summary

To assess the impact of funding for HIV/AIDS on national and sub-national systems, the Global Fund commissioned a study to assess community perspectives on the effects of large-scale HIV/AIDS funding and to determine what challenges, lessons and opportunities this presents. The results from this study are designed to sharpen and clarify understandings of systems effects of HIV/AIDS funding through the assessment of local-level responses in three diverse communities in South Africa: an urban township (Vosloorus), a small town (Grahamstown) and a deep rural area (Obanjeni).

Increased funding has contributed to a rapid growth in the number of organisations undertaking HIV/AIDS activities, most notably CBOs and NGOs. With increasing health financing available, particularly for HIV/AIDS, greater attention needs to be paid to the impact this can have on national and community level processes. This study focuses on three key characteristics of systems effects: additionality, partnerships and sustainability.

***Additionality**:* Additional resources permit a growth in the scale and scope of community-based organisations and, in some cases, can increase their professionalism and foster capacity building. It can also lead to greater accountability, better programme definition and an improved understanding of monitoring and evaluation of programmes at the community level.

However, a lack of local-level co-ordination hampers the value of additional HIV/AIDS financing. While reprioritisation of community activities is to be expected in the face of an epidemic of such proportions, increasing attention to HIV/AIDS may detract from the provision of other key community services.

***Partnerships**:* An impressive number of community-based organisations network with other organisations, yet much counterproductive competition between organisations is noted and mistrust is evident. There is much variation in the level of coordination between government and community organisations, and between community organisations themselves, but on the whole, local-level systems for leading HIV/AIDS response remain weak. Many functional limitations identified by community-based organisations could potentially be overcome by co-ordination at the community level.

There is an urgent need to tackle community level partnerships and invest in community systems strengthening to coordinate this. Much scope remains for partnership formation and promotion at the community level and the development of multi-sectoral partnership strategies may facilitate this.

***Sustainability**:* While some community-level organisations have succeeded in accessing consistent funding to pursue their missions, many organisations struggle with chronic challenges around funding. Day-to-day concerns of sustainability related to the survival of the organisation seem to take priority over longer-term developmental work, such as improvements in staff training, capacity building, infrastructure support and the development of linkages between organisations. Investments in this type of 'systems building' are likely to contribute significantly to organisational sustainability.

The importance of increased financing for HIV/AIDS reaching communities must be highlighted. In the realm of finite resources to fight the HIV/AIDS epidemic, these resources must be efficiently and practically used for the communities who need them to appreciate their full benefit. Ensuring the optimal and efficient use of HIV/AIDS financing is a shared responsibility between donor agencies and national governments.

Key recommendations from this study support the need for:

1. Community-level systems strengthening to better absorb increased funds
2. Commitments by donor and national governments to steadily increase funding to grassroots organisations
3. Capacity development for CBOs and NGOs in human resources and organisational systems
4. Local focal points to coordinate community response
5. Addressing the extent to which activity substitution is occurring

1. Introduction

An estimated five million South Africans were HIV positive in 2004, with the population-wide HIV prevalence rate estimated at 11%[1]. 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).

South Africa has been among the top five recipient nations of HIV/AIDS donor financing worldwide,[2] with more than USD 53 million earmarked by donors for HIV/AIDS response in 2002-2003, alongside more than USD 79 million in allocations by the South African government.[3] With such growth in funding for HIV/AIDS, concern has been expressed as to the potential impacts of such financing on recipient systems, including at the community level. This study, commissioned by the Global Fund to Fight AIDS, TB and Malaria (The Global Fund), aims to review the systems effects of HIV/AIDS financing at the community level. However, this study is not specific to Global Fund financing, and aims to assess overall impacts at community level.

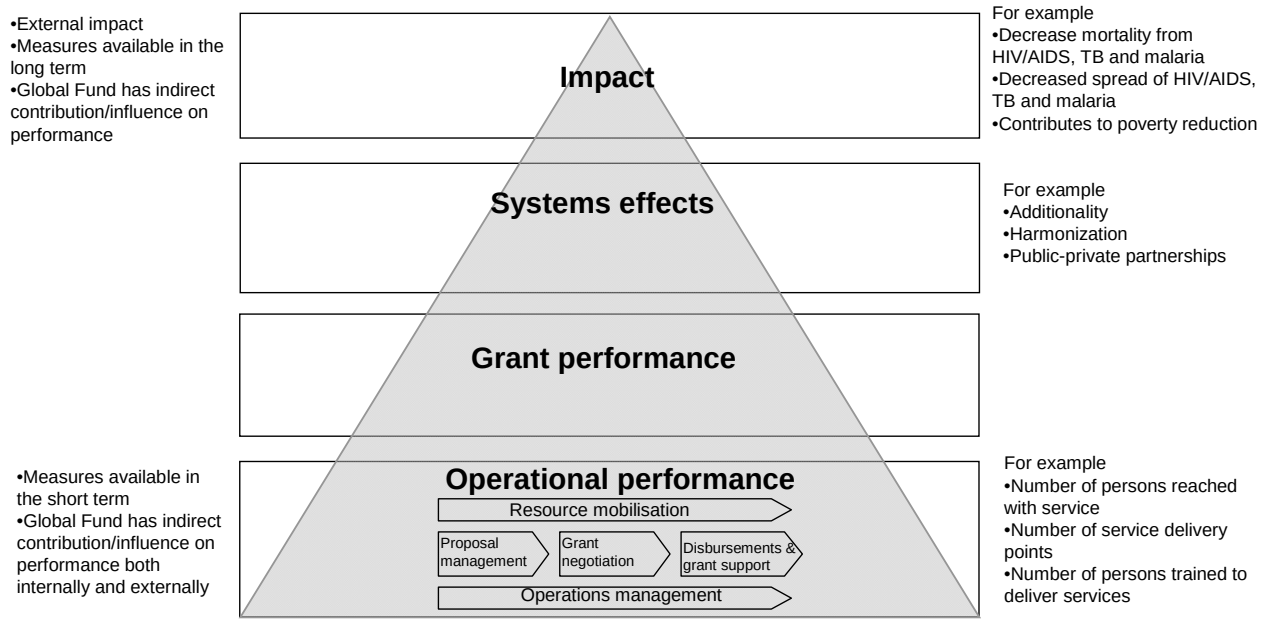
In 2003, South Africa received its first round of Global Fund financing. In 2005, three Round 1 grants, a Round 2 grant and a Round 3 grant are being financed by the Fund in South Africa. Four of these grants were awarded under the HIV/TB component to the National Treasury of the Republic of South Africa. The fifth grant was awarded to the Western Cape provincial health department for its HIV/AIDS component. The total five-year value for all grants amounts to just under USD 234 million, a small part of total HIV/AIDS spending in the country.

1.1 Measuring systems effects of financing: from global to local

The Global Fund's measurement framework (Figure 1) identifies four levels of management focus to assess internal performance and external impact.

[1] Dorrington, R., Bradshaw, D., Johnson, L. & Budlender, D. (2004). *The demographic impact of HIV/AIDS in South Africa. National indicators for 2004.* Cape Town, Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.
[2] UNAIDS/OECD. (2004). *Analysis of aid in support of HIV/AIDS control*. Geneva, UNAIDS.
[3] Ndlovu, N. (2005a). *An exploratory analysis of HIV and AIDS donor funding in South Africa*. Budget Brief No. 155. Cape Town, IDASA AIDS Budget Unit.

Figure 1: Global Fund performance measurement system



The Global Fund has begun a systematic study of potential systems effects of Global Fund financing with a view to three dimensions: additionality, partnerships and sustainability (Table 1). *Additionality* looks at the augmentation of existing activities through a net addition of external financing. *Partnerships* reviews alliances formed between organisations at different levels – within the local community and beyond – describing how these working relationships are shaped by HIV/AIDS funding. Lastly, *sustainability* of financing encourages the continuation of programmatic components beyond the scope of the funding itself. This is an important concept and the Global Fund seeks to promote sustainable implementation over time, both for the grantees and for the Fund itself.

Many of these concepts are defined at the global level and indicators have been developed which permit measurement at a global scale. While these provide much insight into systems effects, the scale at which they operate is likely to preclude a comprehensive understanding of the impact of donor funding at the sub-national and local levels. At these levels, effects on communities are more visible and the real impact of donor financing can be observed.

Because of the many different types of funding for HIV/AIDS that are flowing into South Africa, it is difficult at community level to distinguish Global Fund support from other sources of financing. As a result, this study aims to review the community-level systems effects of HIV/AIDS financing in general, to observe whether such financing is additional and sustainable, and to explore how the formation of partnerships occurs. Measurement of these concepts at the community level is not without problem, and as a result, this work will help to develop meaningful community-based measures for the three dimensions of systems effects under study.

Table 1: Dimensions of additionality, sustainability and partnerships

	Additionality	Sustainability	Partnerships
Global	The Fund should not 'crowd out' or substitute for other donor assistance or inhibit domestic resource mobilisation.	Sustainability of the Fund as a financing mechanism by maintaining financial capacity to meet existing and new commitments through financial and political commitment.	Harmonisation between donor agencies and the international community, as well as technical assistance.
National	The Fund must seek to demonstrate that despite fungibility, and the capacity of finance ministries to direct overall public resources to alternative uses, financing from the Global Fund is a true net addition to intervention against the three diseases.	Financial sustainability so that programmes and activities can be financed, even after GF resources end. Technical and institutional sustainability to ensure continuity of service delivery (such as drug procurement systems in place).	CCM composition and representation as a public private partnership is a fundamental part of ensuring healthy partnerships at country level. Good governance and management, as well as participation and communication between country actors, need to be ensured.
Community	Financing at community level should provide an augmentation of existing services, without substitution. Additionality should be measured through both financial and non-financial means, through growth in human resources for health and capacity building. initiatives.	The reliability and flow of financing is an important part of the stability of community organisations. Efficient use of resources, such as ensuring commodity price efficiencies, may determine sustainability of programmes.	Partnerships between community organisations, as well as between community, provincial, and national-level entities should be encouraged, including forging lines of communication with the ministries of health.

1.2 The community response

The scale of the epidemic, structural limitations of the public health and welfare systems, and the availability of financing and support have all contributed to growing community-level initiatives around HIV/AIDS.[4] These variously aim to support and care for individuals and families directly affected by HIV/AIDS, to ameliorate the impacts of AIDS on communities, and to strengthen attempts to prevent the spread of the epidemic using community associations and organisations as a base of operations.

These responses – which range from informal support groups of relatives, neighbours, or church members, 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 not incorporated in large scale 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 and a number of issues would benefit from closer examination:

- How sustainable are community responses? How can such responses be scaled up?

[4] Birdsall & Kelly (2005) have described the emergence of community-level responses in South Africa.

- How cost effective are community responses?
- How aligned and integrated are they? How systematic are they?
- What funding needs do communities have? How secure is funding for community-based organisations?
- How can such organisations be best supported?

Few systematic studies have been undertaken to address these questions. The current study is motivated by questions related specifically to funding. The need to fund the fight against AIDS and particularly the need to co-ordinate and scale-up international funding efforts led to the formation of the Global Fund to Fight AIDS, TB and Malaria. The Global Fund has tasked its Strategic Information and Evaluation Unit with the responsibility for monitoring the effects of its funding activities. The primary concern is the need to monitor and evaluate the use of funds in producing intended interventions, however there is also a concern to measure the consequences of the availability of large-scale funding on the health sector or other areas of the economy, as well as at the level of community activity.

In the interests of measuring such systems effects, The Global Fund has developed a set of indicators for use at country level. The purpose of this research is to explore the manifestation of systems effects at the community level. We consider the dynamics of community-level mobilisation around HIV/AIDS and the funding factors that are influencing this, as well as looking at the ways that funding issues are shaping community-level responses, how they are influencing partnerships and co-ordination, and what the implications are for sustainability of community-level HIV/AIDS responses.

2. Scope of research

The overall aim of the research was to provide a bottom-up perspective on the systems effects of large-scale HIV/AIDS funding and to produce material that could inform work on such issues at the Global Fund. The objectives included:

- To identify and describe main systems effects of HIV/AIDS funding at community level;
- To consider ways in which such systems effects might be measured;
- To review the set of key indicators developed by The Global Fund in light of findings; and
- To provide community perspectives to supplement global analyses.

Key research questions included:

- What is the HIV/AIDS response to increased financing at community level?
- What key systems effects can be identified at the community level?
- What are the factors affecting absorptive capacity and the optimal use of financing?
- What are the bottlenecks to the better use of financing from a bottom-up perspective?

- What are the real issues in building capacity within communities?
- What are the systems impacts in each of the following domains:

  Additionality: whether additional funding augments existing activities, including changes in the construction of organisational mandates and perceptions. At the community level, whether activities developed in view of additional funding add value.

  Partnerships: at an organisational level, the way in which allegiances, alliances and working relationships are shaped by HIV/AIDS funding.

  Sustainability: whether and how financing contributes to sustainable organisational development over time.

- How might the effects noted be defined and measured?

3. Methodology

3.1 Data gathering

This report draws upon two sources of data from three South African communities: Vosloorus, Gauteng Province; Obanjeni, KwaZulu-Natal; and Grahamstown, Eastern Cape (see section 3.3 for descriptions of each site). These sites provide wide geographical variation, including an urban township, a small town and a deep rural area.

The first source of data is from a survey of local organisational responses to HIV/AIDS in the three communities, conducted by CADRE in 2003/2004. This 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 (years of operation, staff, volunteers, financial management systems, etc.), on the areas of HIV/AIDS response in which it is engaged, on the types of services provided, and on the successes and challenges experienced in AIDS response work. Organisations were identified through a snowballing approach; a total of 179 organisations completed the survey – among them 29 government departments or institutions, 43 civil society organisations (NGOs, CBOs) and 16 faith-based organisations (FBOs).

The second source of data derives from research conducted specifically for this study within the same three communities. In each of the three communities interviews were conducted with individuals fulfilling the following criteria:

- a representative of a development-oriented or community support organisation or association that has become involved in HIV/AIDS work, but not as its primary mandate;
- a representative of a community youth group involved in HIV/AIDS work;

- a member of a co-ordinating body for community HIV/AIDS services;
- a community member who knows the community well and has been involved in community affairs over a long period of time.

First, respondents were required to speak about their own experiences as well as to speak about the perceived experiences of others. Second, interviewees were requested to take note of any experiences or events that they came across for a period of three weeks and were then re-interviewed to gain a more experience-near understanding of the issues of concern to the study. Third, a selection of community-level activities which respondents were engaged in were attended and observation notes were taken of phenomena of interest to the study.

3.2 Data capture and analysis

Data from the community survey were captured in Excel and analysed using SPSS. Qualitative data was captured separately and analysed for key themes.

Interviews conducted specifically for this report were tape recorded, translated (where necessary) and transcribed. Transcriptions, the respondents' notes and observation notes were captured for analysis with Atlas.ti, a computer-aided qualitative data analysis software. The data was coded using pre-defined categories determined by the research questions and further categories were added as suggested by the data.

The final report, written by both CADRE and the Global Fund, used data from all these sources.

3.3 Site descriptions

This report draws upon data from three South African communities: Vosloorus, a large urban township in Gauteng Province; Grahamstown, a small town in the Eastern Cape; and Obanjeni, a deep rural area of KwaZulu-Natal. The three selected sites are distinct from one another in terms of size, type, population density, geographical location, infrastructure, and other characteristics. This potentially allows for observation of variation between types of communities, including different forms and levels of community mobilisation around HIV/AIDS within these communities, and different effects as a result of large-scale HIV/AIDS funding.

Vosloorus is a large urban township in the Ekurhuleni Metropolitan Municipality outside Johannesburg.[5] It has a population of approximately 150,000 people (almost entirely Black African). The township has a fairly well-developed infrastructure: 72% percent of the population lives in a house or brick structure on its own stand (predominantly government 'matchbox' houses) and 92% per cent of dwellings are connected to sewer systems. Like many South African communities, however, Vosloorus is facing the interlinked challenges of unemployment, poverty and HIV/AIDS. Thirty-six per cent of Vosloorus residents aged 15 to 65 are employed and 15% are students, while 41% percent describe themselves as unemployed or unable to find

[5] Data on Vosloorus and Grahamstown based on Statistics South Africa 2001 Census data.

work. For this and other sites no local-level estimates of HIV prevalence are available. The all ages HIV prevalence level for Gauteng Province in 2002 was 10.7%.[6]

Grahamstown is a small town in the Eastern Cape. The combined population of the town centre – which is dominated by a business district and Rhodes University – and two outlying townships of Rhini and Fingo Village is approximately 60,000 people. Seventy-eight per cent of the population of Grahamstown is Black African, 12% is Coloured, and 10% is White. Grahamstown dates to the early 1800s and the outlying townships are long-established, although some of the dwellings were recently built as part of the Reconstruction and Development Programme (RDP). 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%). Twenty-seven per cent of Grahamstown residents aged 15 to 65 are employed and 24% are students, while 34% percent describe themselves as unemployed or unable to find work. The all ages HIV prevalence level for the Eastern Cape in 2002 was 6.6%[7].

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 8,000-10,000 people. Obanjeni is a developing area constituted by scattered homesteads, known as 'imizi.' It is headed by a Tribal Authority or 'inkosi' (chief). 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. The all ages HIV prevalence level for KwaZulu-Natal in 2002 was 11.7%.[8]

The following table presents HIV prevalence for the province in which the study site is located as well as selected findings from an April 2004 survey, conducted by CADRE, investigating perceptions and responses to HIV/AIDS among youth in Vosloorus, Grahamstown and Obanjeni. The data is drawn from a panel survey of 752 youth, aged 16-27 years, selected through a systematic probability sample procedure in the three communities.

Further discussion of individual responses to HIV/AIDS in the three sites is provided in the Appendix to this report.

[6] Shisana, O. *et al*. (2002). *Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media. Household survey 2002*. Cape Town: HSRC. p46.
[7] Shisana *et al*. (2002).
[8] Shisana *et al*. (2002).

Table 2: Behavioural and attitudinal survey data for three community sites (%)

	Vosloorus	Grahamstown	Obanjeni
All ages HIV prevalence rate for province (2002)	***10.7***	***6.6***	***11.7***
Geographic description	Urban township	Semi-urban town	Deep rural area
Behavioural surveillance data for n=752 youths aged 16-27 years			
Has ever had sex	87	89	69
Has ever used a condom (of those who have had sex)	94	86	78
Used a condom at last sex	77	60	53
Always uses condoms	44	28	14
Ever had an HIV test	25	35	27
Knows where to go for HIV test	89	75	53
Decided to have fewer partners	14	14	13
Knows someone who is HIV-positive	58	86	41
Helped care for a person who is sick with HIV/AIDS	17	18	16
Would tell friends if found out that HIV positive	56	71	63
Agree or strongly agree that it is possible to live a happy life, even if one is HIV positive	80	83	66
Agree or strongly agree that people should talk openly about HIV/AIDS in the family	92	91	85

4. Background on HIV/AIDS response

4.1 The national context

In 2004 there were an estimated 25 million people living with HIV in sub-Saharan Africa – almost two-thirds of the global total of people living with HIV.[9] South Africa is among the countries most seriously affected by the epidemic. In 2002, South Africa had an estimated HIV prevalence rate of 11% among the general population[10] and in 2004 the HIV prevalence amongst female antenatal clinic attendees aged 15-49 was 29.5%.[11]

There is considerable variability in HIV prevalence throughout the country, with variations occurring in relation to demographic contexts, such as settlement type and province, as well as in relation to demographic categories such as age, sex and race.[12]

HIV prevalence rates have escalated rapidly in South Africa since the early 1990s in spite of a comparatively well-developed health care infrastructure, well-established interventions such as those addressing sexually transmitted infections (STIs) and condom distribution, a policy environment that includes a comprehensive HIV/AIDS plan, and a constitution that emphasises basic human rights, including rights related to HIV/AIDS.

[9] UNAIDS. (2004). *Report on the global AIDS epidemic.* Geneva: UNAIDS.
[10] Dorrington, R. *et al*. (2004).
[11] National Department of Health. (2004). *National HIV and syphilis antenatal sero-prevalence survey in South Africa 2004*. Pretoria: Department of Health.
[12] Ibid. p46-55.

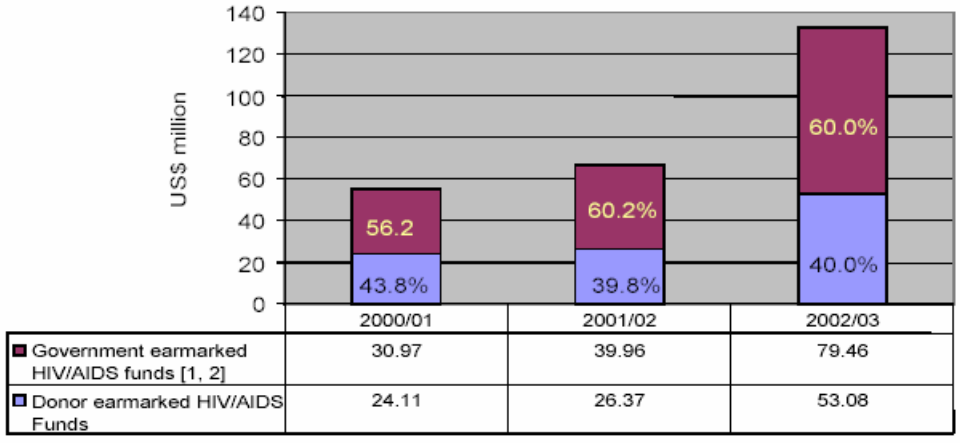
The national response to HIV/AIDS in South Africa has relied heavily upon the public health system for interventions such as condom distribution, Voluntary Counselling and Testing (VCT), prevention of mother-to-child transmission (PMTCT), treatment of opportunistic infections, and more recently, the roll-out of anti-retroviral therapy (ART). These initiatives have been accompanied by communication activities using a range of media.

While HIV prevention campaigns have been ongoing and extensive, none of these interventions have contributed sufficiently to HIV prevalence reduction. Equally, although treatment, care and support are available, there still appear to be glaring gaps and deficiencies. It has taken sustained and determined pressure from civil society groups to bring about broader access to treatment for HIV-positive South Africans who rely on the public health system.

4.1.1 Funding context at the national level

The proportion of the South African government budget dedicated to HIV/AIDS has increased over the years, as depicted in Figure 2. The proportion of external funding relative to the government budget has remained more or less constant, reflecting comparable growth in both, suggesting true financial additionality is occurring at the national level.

Figure 2: Comparison of donor and government earmarked HIV/AIDS funds for 2000-2002[13]



More recent or comprehensive data is not available, and the above data excludes smaller funders (such as private foundations), private sector investments in HIV/AIDS response, and local-level contributions through churches, community associations and charities. Tracking HIV/AIDS funding is a difficult task, because there is no centralised reporting mechanism in place that captures the various flows of external aid. Moreover, funding is not channelled in a uniform way – some flows through government departments, while others flow directly to NGOs. A donor matrix maintained by the Department of Health provides a snapshot of the commitments of the largest bilateral and multilateral donors, but it is not regularly updated and

[13] Ndlovu, N. (2005a).

reflects committed amounts, rather than actual disbursements. There are also challenges in 'annualising' amounts of funding committed over multiple year periods.

In South Africa, approximately 60% of HIV/AIDS funding comes from domestic governmental expenditure. Other countries in the region rely much more heavily on donor sources for HIV/AIDS funding than on domestic revenue. For example in 2001, 90% of HIV/AIDS funding in Mozambique came from external bilateral and multilateral donors.[14] UNAIDS estimates that about 80% of HIV/AIDS funding in sub-Saharan Africa will have to come from external sources.[15]

4.1.2 Challenges in disbursements and absorptive capacity at the national level

Spending of committed government funds has been a significant problem in the past and remains so in some provinces. Spending of bilateral donor funds for HIV/AIDS is reported to be slower than the spending of government funds. The reasons for this[16] are of interest in the context of this research. First, donor funding is usually provided as ring-fenced or earmarked resources, made available for very specific purposes and objectives. Typically such funds come with strict conditions to be satisfied when spending the money. According to Ndlovu (2005), 'Although earmarked funding is beneficial in ensuring that new and critical projects are funded, donor funds may hinder or clash with national government priorities, leading to decreased flexibility for implementers when spending on vital local priorities'.[17] Second, spending of donor funds is hindered by weak provincial health systems and insufficient capacity of the government to commit the money to augmenting key programmes.

Absorptive capacity, rather than availability of resources, is increasingly becoming the key funding issue in South Africa.[18] Provincial governments in South Africa, which are responsible for most of the HIV/AIDS spending, are faced with the challenge of increasing spending at programme level. There is a strong need to invest in development of governmental and non-governmental systems to ensure that resources are utilised effectively and efficiently.

4.1.3 Service delivery partnerships

Government spending on HIV/AIDS is mostly expended through the services of the main provincial government departments active in HIV/AIDS, namely Social Development, Health and Education. However, increasingly money is being spent on supporting partnered organisations that are funded to provide particular services. The most notable example is home-based care, where provinces across South Africa have provided funding to NGOs to provide training and services. But there are many other examples, including NGO capacity building programmes, HIV/AIDS education, community mobilisation, research and VCT, where government has procured services of non-governmental partners.

[14] Ndlovu, N. (2005a).
[15] UNAIDS. (2004a).
[16] As described by Ndlovu, N. (2005a).
[17] Ndlovu, N. (2005a).
[18] Ndlovu, N. (2005a).

Although there is official endorsement of 'partnerships against AIDS' and there are many partners with service level agreements with provincial governments, there does not appear to be a systematic framework for supporting partnerships. In many cases the types of support necessary for local-level partnerships and for partners to work together towards integrated service delivery are not in place. Increasingly provinces are making funds available to districts for contracting NGOs to deliver services, but districts usually lack the capacity to recruit and contract local organisations and to monitor contracted work. In this context it is of interest to understand local-level perceptions relating to the availability of funding and the various contingencies on which this rests.

4.2 Community context

The scale of the HIV/AIDS epidemic in South Africa – coupled with 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 respond to various aspects of the epidemic. This includes the visible and growing need to support and care for people living with HIV/AIDS – and others, such as children, who are affected by the epidemic – as well as engagement with prevention, treatment, and rights-related activities.

4.2.1 Organisations responding to HIV/AIDS

Together with an increase in financing, there has been a great increase in community organisations responding to HIV/AIDS. Whilst national and global policy approaches focus much attention on large-scale and centralised initiatives, and pressure groups such as the Treatment Action Campaign have become synonymous with 'civil society' responses on AIDS, a broad-based array of groups and activists have emerged organically at the local level to cope with some of the pressures being created by the epidemic. These responses range from informal support groups and networks of caregivers through to organised community structures that provide a range of services to infected and affected individuals.

An audit of community-level activity on HIV/AIDS conducted by CADRE in the three communities in 2003/4 identified 59 NGOs (non-governmental organisations), CBOs (community-based organisations) and FBOs (faith-based organisations) involved with AIDS response activities. Among these were home-based care organisations, hospices, support groups and PWA associations, women's groups, youth groups, training organisations, community centres, and churches and faith-based initiatives. The number and types of organisations identified in each site are presented in the table below. Non-governmental and community-based organisations outnumbered faith-based organisations at every site, and fewer organisations of any kind were noted in the rural area compared with urban areas.

Table 3: Number of organisations reporting HIV/AIDS activity

	NGO/CBO	FBO	Total
Grahamstown	23	7	**30**
Obanjeni	4	1	**5**
Vosloorus	16	8	**24**
Total	**43**	**16**	**59**

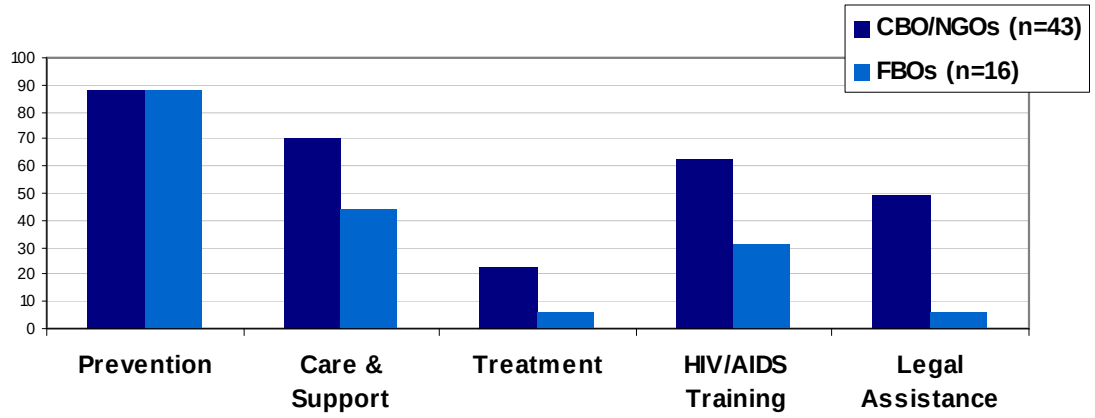
In understanding the local-level funding situation it is important to consider local economic conditions. Given increasing levels of unemployment, entry into the world of organised community support and development through funded programmes is considered a means of subsistence. Opportunities for training and small stipend payments are sometimes available through work with NGOs and CBOs, and increasingly CBOs have opportunities to obtain financial support. Thus, in addition to whatever philanthropic motives may drive people to involvement in community-based HIV/AIDS work, there is ample self-interest attached to funded community development initiatives.

4.2.2 Services provided by community organisations

Organisations at the local level provide a broad range of services across the core response areas of prevention, care and support, treatment, and legal services. As Figure 3 shows, prevention is an area of activity for the greatest proportion of organisations, followed in descending order by care & support, training, legal assistance and treatment.

The study found that almost 90% of community organisations conduct HIV prevention activities, with the most common approaches being promotion of condom use (82%), abstinence (79%), behaviour change (82%) and life skills (71%).[19] Specialised prevention services such as voluntary counseling and testing, prevention of mother-to-child transmission, post-exposure prophylaxis and clinical care (e.g. treatment of sexually transmitted infections and opportunistic infections) are provided by a limited number of groups, which tend to be government institutions.

Figure 3: Percentage of community organisations involved in response areas



[19] Faith-based organisations place greater emphasis on abstinence (100%) and sexual behaviour change (86%), and less emphasis on condom use (64%).

A significant proportion of community organisations - 70% - provides care and support services. The findings from the community audit suggest that NGOs, CBOs and FBOs are more involved in core care and support services than are government institutions, particularly in the areas of nutrition support, care for orphans and vulnerable children, home-based care, and household assistance.

At the time of the study in mid-2004, during the early stages of the national ARV roll-out, community organisations were not centrally involved with medical aspects of treatment, although a number did report involvement with treatment literacy activities.

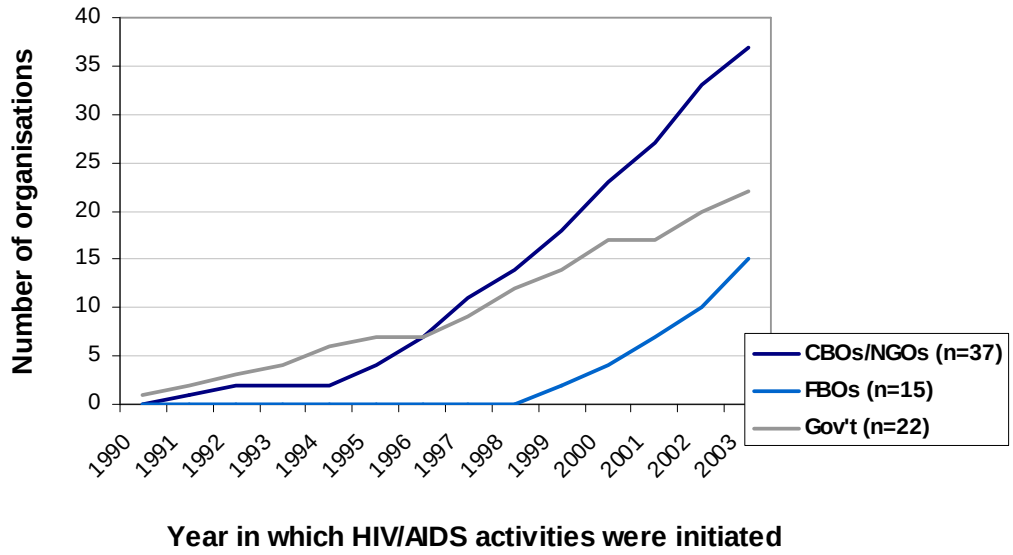
Table 4: Summary table of key services provided

Area of Intervention	Services Provided	
Prevention	Promotion of condom use Life skills Condom distribution	Promotion of abstinence Sexual behaviour change
Care & Support	Counseling Emotional care Home-based care Household assistance Pastoral care	Support groups Nutrition support Support to orphans & vulnerable children Palliative care
HIV/AIDS Training	Behaviour change Counseling	Life skills
Legal Assistance	Referral services	Support in reporting cases to the police
Treatment	Support to integrated management of AIDS/TB/STIs	DOTS support for TB Treatment education

4.2.3 Rapid growth of AIDS organisations

The growth of HIV and AIDS responses in the three communities is reflected in the chart below. This represents the cumulative number of organisations involved in AIDS responses through 2003, according to the year in which organisations first began their HIV/AIDS activities. 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 gradually and linearly, the growth of NGO/CBO and FBO responses has risen relatively sharply. Since 2000, there has been a 29% increase in HIV/AIDS initiatives among government agencies compared to a 61% increase in NGO/CBO activity and a 275% increase in FBO activity.

Figure 4: Growth of community organisations working on HIV/AIDS in three studied communities



There is corroboration of these findings in the database of non-profit organisations registered with the Department of Social Development,[20] and also in the National AIDS Database compiled for the Department of Health by the Centre for HIV/AIDS Networking (HIVAN) at the University of KwaZulu-Natal. 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%.[21]

Similar patterns of growth in civil society 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.[22]

It is unlikely that this trend will abate. As the epidemic deepens its impact on communities, the 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

[20] Accessible at http://www.welfare.gov.za/NPO/npo.htm
[21] 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).
[22] Thornton, R. (2003). *The Uganda HIV/AIDS success story examined: The role of civil society and linkage to social and economic development.* AIDS Mark/USAID.

equipped to deal with these needs, or are dealing with these needs in the absence of sufficient government action in the area.[23]

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 period shows that they are already heavily involved in providing complementary care and support services.

The needs for HIV/AIDS response are plainly evident to community-level organisations and there have been strong exhortations by funders to mainstream HIV/AIDS in development initiatives. New organisations are forming and existing ones are incorporating HIV/AIDS responses. It is important to take stock of the perceptions and experiences of these emerging organisations and projects in relation to resource needs and to understand how these developments can be supported, optimised and sustained.

5. Systems Effects of the HIV/AIDS Funding Environment

5.1 Availability of funding: money for AIDS 'everywhere'

It appears to be understood at community level that large amounts of money are being allocated by both governmental and non-governmental actors – national and international – in support of AIDS responses in South Africa. Unprompted awareness of the existence of US government and Global Fund money for AIDS-related programmes, in particular, was high among respondents, and there were also frequent references to spending on HIV/AIDS by various arms of the South African government.

In many, but not all cases, this translates into awareness of the availability of sub-streams of funding to support the work of NGOs and community-based organisations involved with AIDS response. Some respondents confidently expressed views that there is a lot of money 'out there' for AIDS-related activities, including 'surplus' funds that are allocated, but not disbursed.

Distinctions should be drawn, however, between generalised awareness of the availability of funds for HIV/AIDS activities at a national and provincial level and the actual availability of financial support for organisations working at the community level. As one respondent noted, 'Well, I can say that we are not receiving any funding at all, and I know of nobody that is receiving it.'[24]

Research in these three sites suggests that, in practice, many organisations on the ground have had partial or no success in tapping into HIV/AIDS funding streams, for reasons which are addressed in section 5.2 below. This contributes to confusion about where all this available funding goes and whether it is being spent appropriately (see section 5.3).

[23] cf. Kelly & Mzizi. (2005).
[24] Community support orgn KZN

Some key findings from the community audit:

- Funding and resources are a chronic problem for many community-level organisations working in the area of HIV/AIDS response: 46% of the community organisations surveyed named funding as their biggest challenge;
- The nature of the problem varies: for some organisations the problem is that funding flows are erratic and difficult to secure across project cycles; others have had no success in accessing external funding and operate solely on donated goods and volunteer efforts;
- When asked to cite specific challenges they experience in relation to funding and resource mobilisation:
    - 39% mentioned constraints in funding (financing)
    - 27% mentioned the need for specific resources related to their work (food parcels, office equipment, condoms, educational materials and/or transport)
    - 14% mentioned shortages of volunteers, staff, caregivers or trainers (or an inability to pay them)

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). Organisations struggling to mobilise resources commented that a lack of funding can translate into an inability to conduct activities, to visit project sites, and to retain staff and volunteers. In a larger sense, funding constraints also impede organisational development and place community groups on a permanent 'war footing' in the on-going battle to cover expenses, to identify possible channels of support, and to prepare proposals to access that support.

> *Funding to me, it doesn't seem as if there is a problem because we all know that money is there. We do have money that was contributed by other donors to the South African government.*[25]
>
> *There is money for HIV/AIDS everywhere. It's a matter of one standing up and persisting until she gets it.*[26]
>
> *There are many organisations who are doing research on HIV/AIDS and they are getting a lot of funding. Lots and lots of money.*[27]
>
> *…at the end of the financial year, you will find some statement saying that the Department of Education has underspent and there are funds left for HIV/AIDS.*[28]

5.2 Access to funding: challenges exist

The experiences of community-level organisations in terms of accessing HIV/AIDS funding are not uniform. The large growth in the number of HIV/AIDS organisations, as well as the fact that

[25] Community rep KZN
[26] Community Support orgn EC
[27] Community rep EC
[28] Community support orgn EC

much community-level activity is supported, in one way or another, by external sources of financing shows that some funding clearly is penetrating down to the local level. Certain organisations working at community level have diversified funding profiles and receive support from a variety of donors for different projects with overlapping project cycles. Yet many other organisations struggle to stay afloat and carry out their activities in fits and starts, limited by the extent of the resources which they can mobilise locally (donations of goods, access to free transport, inputs from volunteers). For these groups, therefore, the challenges around resource mobilisation appear to be less about an absence of resources as such, than about difficulty in gaining access to them.

This section considers some of the factors which seem to mediate the experiences of community-level organisations in accessing HIV/AIDS funding. Many of these factors appear to relate to an organisation's positioning – its awareness of funding opportunities and its institutional track record – and to its capacity to engage in the 'funding process.'

> *How do you access those kinds of funds if they are sent to the governments of the respective countries? How do they actually filter down or through to the people who really need that kind of assistance, those who are HIV positive and those who are affected directly by HIV/AIDS?*[29]

5.2.1 Playing the 'funding game': experience is critical

Interviews suggest that familiarity with the funding process – including prior experience receiving funding – is a factor that may inform the degree of success organisations have in accessing financial support for HIV/AIDS activities. Newly established groups, groups in rural or remote areas, and organisations without a funding 'track record' sometimes struggle to understand application procedures and requirements, donors' funding priorities (and therefore the suitability of their own application), and how to complete the required documentation.

Groups that are new to the 'funding game' do not necessarily know how to formulate their activities in a way that aligns with donor expectations. This includes, for example, the ability to use terminology and concepts that are common in funding and development circles, and the ability to frame issues and approaches with reference to these prevailing discourses.

> *Maybe we can write what is the problem, but there are other technicalities when you are writing a proposal. [For example,] 'is there a market?' You see, when you say, 'is there a market' [for your services] to a person who is not educated, you are confusing him. The forms have to be simplified, or they must be relaxed.*[30]

Lack of clarity about funder priorities and eligibility requirements may also contribute to organisations mis-targeting applications for funding. Organisations with limited or no funding history may struggle to assess their suitability for a particular funding opportunity (e.g. they may choose to apply for an announced opportunity that is clearly oriented on well-established

[29] Community rep EC
[30] Youth orgn KZN

organisations), or may not be aware of funding opportunities that are better suited to their profile and organisational capacity.

The experiences of groups that are struggling to attract funding contrast quite sharply with those that have been successful in securing funding and use this as a starting point from which to build the organisation further. For example, a youth dance and drama group that has received funding consistently from the Department of Health over a period of several years has used this 'stability' to search proactively for additional sources of funding to supplement that received from the Department and to diversify its funding profile in the event that the Department ceases its financing.

5.2.2 Donor transparency of proposal process

The experiences of community organisations in their interactions with donors seem to vary tremendously, with a fairly clear distinction emerging between those that receive funding and those that have failed to access it. Among the latter, many respondents voiced deep frustrations about non-transparency and non-responsiveness on the part of donors in relation to applications for funding. In several unrelated interviews, respondents recounted similar stories of submitting funding proposals, never to hear anything further from the donor about their application – not even an acknowledgement of receipt. This lack of acknowledgement was repeatedly mentioned by groups in all three sites as a particularly demoralising and demotivating aspect of the funding process.

The fact that this point was so frequently raised as a concern suggests that there are indeed obstacles to accessing funding at the local level which may relate to the inaccessibility of donors to local communities, technological or communications challenges, and/or lack of clarity around application and notification procedures. There is a need for the donor community to present a transparent and much simplified proposal process which provides, among other things, constructive feedback to community organisations on unsuccessful submissions.

> *As poor organisations working for the poor affected and infected communities, you devote your time in writing the proposal with limited resources and at the end of the day, you don't even get an acknowledgement that they received your proposal.*[31]
>
> *Sometimes you send a proposal to … some donors. They don't even write a letter of acknowledgement, saying that they have received your funding proposal. You will phone several times, but you will not get any response.*[32]

5.2.3 Criteria and priority areas for funding can define organisational agendas

Another factor which seems to inform community organisations' access to funding is alignment between donors' criteria and priority areas for funding, on the one hand, and the services

[31] Diary entries EC
[32] Community support orgn EC

provided by organisations on the other. This issue of alignment can work in favour of or to the detriment of organisations on the ground – often in ways that they may not anticipate or understand.

Several organisations noted that the criteria or conditions established by donors in relation to the projects they support can affect the success of funding applications. Organisations whose on-going work aligns with donor priority areas may find that their journey to accessing funding is a quick and straightforward one, as illustrated in the second example in the box below.

> *You will find that there are criteria – different criteria put down by the funder. For instance, we once applied for funding from the… South African Catholic Bishops' Conference. One of the criteria was that they don't fund organisations that distribute condoms. So we didn't get their funding as a result of that. … We made arrangements, we drafted a proposal, we invited the nuns for consultation and they seemed to be very interested in our programme, but the issue now was the issue of condoms. They said that they could not fund us if we are talking about distributing condoms to the kids.*[33]
>
> *We started as volunteers, we wanted to work for the community. Then one day one person visited from the Department of Health dealing with projects and gave us the forms and explained to us as to what to do to get funding.*[34] *… The person said that we must go to the schools and talk to children about HIV/AIDS and express our views, and after that we must ask for thanksgiving letters to show that we visited those schools, indicating everything that we did and that should be in writing. Just to show that our work is impacting on the school children and that is the way that we can secure funding from them.*[35]

5.2.4 Types of funding mechanisms

One factor that must be considered in relation to access to funding is that of the suitability of prevailing funding mechanisms for channelling HIV/AIDS funding down to the community level and ensuring that funding distributed to civil society organisations does not flow exclusively to large, established NGOs. There need to be opportunities for new and evolving organisations to access funding in small amounts in order to build up an institutional track record with funders. For the most part, such mechanisms remain elusive, with the exception of a few existing models.[36]

The fact that funding from above doesn't seem to penetrate down to local levels is understandable given existing trends of donor support, including reporting requirements and administrative overheads generated by grant and fund 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'

[33] Community support orgn EC
[34] Youth orgn GP
[35] Youth orgn GP
[36] For example, the organisational mentoring model promoted by Development Cooperation Ireland, or the funding conduit arrangements evolved by the Children In Distress Network (CINDI).

grants management by providing block grants to umbrella organisations, including provinces that can sub-contract to local organisations. Even in this case, however, reporting and financial accountability requirements apply and many small community organisations do not have the programme track record or financial systems in place to break into the 'funding game'.

> *I do not get to understand exactly how this whole system of funding is streamlined, so that it becomes very accessible to people who need it. I am saying this simply because of the fact that you find that major funding is in the hands of the government and organisations are struggling to access funding for HIV/AIDS from private donors or private funders. So the situation when it comes to funding in South Africa, you know, for me it's made to be a little bit difficult for the ordinary people on the street. I don't know how possible it is for them to be able to access funding on their own.*[37]
>
> *One of the things that we have seen more particularly us as the black people, is that we don't get funding because we lack skills to write proposals. And if you can go around here in town there are so many white people who have got some…some CBOs or NGOs and they get funds from local companies. Us, because we lack skills we can get nothing. Why? Why….? Because we cannot write all these things that they need.*[38]
>
> *They will try and put in some proposals, but they have never been considered. They don't even get the 'we regret,' or anything, you see? And they try to consult other entities on how to write proposals, and they will do exactly how the experts told them, but they still get nothing.*[39]
>
> *Ours and others' experiences in trying to access funding has been a long drawn out process and bureaucratic red tape.*[40]

5.3 Allocation of funding within the community

Despite increases in HIV/AIDS funding and a growth in the number of organisations working on HIV/AIDS issues, concerns exist about the allocation of funding at community level. Disparities exist, for example, between organisations in the same community undertaking similar work: it is not unusual for one organisation's efforts to be well-resourced and supported, while other organisations provide the same services on a purely voluntary basis. While the previous section discussed factors that may influence individual organisations' access to funding, this section considers broader dynamics which may shape which types of organisations receive funding and how.

5.3.1 Issues of ownership: demand vs. supply-driven funding

One of the major arguments in favour of supporting local-level responses to HIV/AIDS is that community organisations are in touch with local needs and have evolved models of activity which are suitable for the contexts in which they work. Implicit in this view is the idea that local-level HIV/AIDS responses should be driven by and owned by the community itself to the greatest degree possible. Of interest, therefore, is the extent to which the availability of

[37] Community rep EC
[38] Youth orgn KZN
[39] Co-ordinating body KZN
[40] Diary Exercise GP

HIV/AIDS funding allows for and strengthens local ownership of these responses by enabling the implementation of activities driven by demand within communities themselves – or, conversely, the degree to which external funding may in fact undermine local ownership by prescribing the shape and form of 'fundable activities' in accordance with priorities set outside the community itself.

It is clear that there is strong demand within communities for HIV/AIDS activities of many different sorts, as evidenced by the organic emergence of community initiatives around HIV/AIDS – many of which began as purely volunteer efforts. It is also evident, as discussed earlier, that there is funding available to support such activity. What is more difficult to unravel is the interplay of these elements of demand (needs) and supply (opportunities) and the extent to which one or the other can be said to be a driving force.

Although there are certainly examples of organisations that succeed in accessing funding to support their own vision and programmatic approach, there is also strong evidence to suggest that many organisations are altering the profile of their activities in response to the availability of HIV/AIDS funding (see Section 5.4). This includes pursuing opportunities, such as tenders or bids, which do not necessarily align with or add value to an organisation's core work, but which can result in a quick and relatively easy contract. In other words, the availability – or 'supply' – of funding from an outside source for a product conceptualised outside the community can attract the attention of organisations whose own understandings of community needs may be quite different.

To use an example provided by one respondent, the Department of Health announces a tender to produce T-shirts for World AIDS Day, and specifies exactly what to print on the T-shirts. Organisations that apply for this tender do so 'just for the sake of getting [it]….It's not necessarily about the intention that [they] are going to cause an effective change in behaviour. For [them] it's just to deal with that tender and end of story.'[41] The respondent continues: 'There is no linkage really when it comes to this thing about what you are existing for, and what is the government saying, and what the communities themselves are saying.'[42]

The same respondent drew a powerful parallel between the position of African nations that accept international assistance for HIV/AIDS despite certain conditionalities (e.g. funds to be spent on patented medications only) and institutions at community level that will do the same thing in relation to donor institutions. In both cases, he notes, it is desirable that needs and priorities be articulated by the recipients themselves, but this is not always the case.

Related to this is the perception at community level that competition for HIV/AIDS funding is acute, and that the competition is not necessarily rooted in a desire to respond better to needs, but rather to outperform other organisations in accessing funds. In other words, the imperative

[41] Community rep EC
[42] Community rep EC

to access available funds (for whatever designated purpose) may become more of a motivation than ensuring considered responses to particular needs.

The interplay between 'demand' and 'supply' is highly complex and it would be a mistake to conclude that HIV/AIDS responses are driven predominantly by trends in available funding – although this is certainly an important influencing factor. Because the needs are so great and because the available resources are circumscribed in both amount and designated use, it appears that elements of need become translated in relation to available opportunities.

> *If countries agree to whatever is said to them by whoever is going to be bringing money inside, then who are we then as institutions not to fall in the same trap? Because we are the ones on the ground who are really struggling and suffering, so any piece of cent that comes our way – we'll jump on it. So funding has its own problems, not only for the institutions like ourselves, but also for the governments of the countries in Africa. If a major funder comes in to say, 'I want to fund research on this,' people will go and take that money. But it's supposed to be an agreeable kind of a thing to say, 'Okay, you want to come and do research, then let me see what kind of research you are doing and then I will input on that, because I know the situation better than you do.' … So, in a nutshell I am saying that funding can be very helpful; funding can also be very destructive in a sense, because - let's be honest here, very honest - hungry people will take anything that comes their way. Desperate people will take anything that comes their way.*[43]
>
> *The competition on its own is not necessarily a bad thing. If it were competition to say who is going to be the most effective, then that would be a very healthy competition…. But when they start saying…who's got the muscle to deliver, or who is supposed to be getting more money and all those kind of things, then it becomes totally something different, because [Organisation 1] will be fighting against [Organisation 2] to have much more resources…. That's not the issue - the issue is about servicing the people; it's about making the real change…. But when we all want to do it for the sake of doing it because there is money that is coming in, then we are missing it.*[44]

5.3.2 Institutional capacity

Institutional capacity appears to be a factor which mediates the allocation of funding at community level. Organisations with a demonstrable track record in project implementation and service delivery are better positioned to receive funding than relatively less experienced organisations that do not have a documented history of programme activity, for example, or a verifiable track record in financial management.

Capacity issues relate to both physical infrastructure – for example, having an established office, a bank account, and access to communications technology – and to the ability to deliver services. Organisations that lack these elements are at a disadvantage in relation to NGOs that may be affiliated to a larger network or other community-based groups that have built up a base of resources and operational systems. In this situation it is challenging for newly established groups to access small-scale funding on their own in order to build their experience.

[43] Community rep EC
[44] Community rep EC

This points to a need to review existing mechanisms for channeling funding to the grassroots level (see Section 8.3). Small-scale funding is often path breaking in the sense that it builds the capacity and experience of new organisations, but this type of developmental support is intensive to roll-out and manage.

> *If the company is looking for proposals, they are looking for somebody who is big and somebody who has received the funds before, you see.*[45]
>
> *Maybe they want someone with an office – it's a problem. How can you get an office in a rural area? There is no electricity, no phones – you use only your cell phone. It is a problem.*[46]

5.3.3 Personal or institutional connections

The research revealed significant levels of confusion and misinformation about the way in which HIV/AIDS money is spent and allocated. As noted above, there seems to be a clear understanding that large amounts of money are flowing into South Africa for HIV/AIDS activities, but it is not evident to many people 'where this money goes'.

This lack of clarity may feed into the frequently heard supposition that HIV/AIDS funding flows to organisations that have links with government structures or personal ties with officials who are responsible for allocating HIV/AIDS funding. This may also relate to an awareness of the political pressure on government departments to disburse allocated funding. Because NGOs, for example, are often contracted by government to deliver services, there is a perception in some quarters that these contractual arrangements may be made on the basis of expediency (e.g. contracts are concluded with known entities), rather than merit.

> *Maybe it is given to those people who are well known to those top leadership.*[47]
>
> *There are those individual organisations which are connected with some other managers within the department, who always [are] getting some funding.*[48]
>
> *So there was a lady there from the Department of … Health, who was heading that project. That lady was there at our meeting and we submitted documents, only to find that it was even difficult to talk to that lady. Well she was just having no time, always having no time, but she can talk to some other people, but to some other people she was having no time. Then it made me to suspect that funds are given to those people who are known to somebody, not the people who are serving the community.*[49]

5.4 Additionality

Additionality is defined as the condition that external assistance fully augment local investment that would have occurred without that assistance. While the term is most typically used in relation to extra-governmental funding commitments for development programmes at a national

[45] Youth orgn KZN
[46] Youth orgn KZN
[47] Community support orgn KZN
[48] Co-ordinating body KZN
[49] Community support orgn KZN

level, it also has great relevance at the community level. Monitoring indicators with respect to additionality might include 'displacement of governmental or other internal funds to other uses' or 'evidence that the funding is not causing crowding out of other sources of funding'.

5.4.1 Organisational capacity needs to be addressed alongside financing

From the review of community HIV/AIDS programmes, it appears that it is relatively easier for organisations to obtain funds for the costs of equipment, training, services and consumables, than for salary and administrative costs and recurrent general costs associated with the functioning of the organisation. This is not so much a problem for small operations with few overheads and little infrastructure, but as organisations are funded to run larger programmes, these needs grow and the organisations become unviable without core funding. They may even accumulate equipment without the funds to cover staff costs to use it. A case in point is an AIDS support centre which was donated a vehicle for transporting clients, but where none of the staff were able to drive. This is most likely to happen in the case of specific donations, and it would not usually be the case that a funder would provide earmarked funds when there is no plan to put these funds to use. But it is often the case that organisations will fund different parts of their programme from different funding sources and because of the failure of one proposal, it will not have the means to utilise that which is granted by another proposal.

Training is another area that, while seemingly fulfilling the requirement of augmentation, may not add much value to organisations because it is 'tacked on' and not integrated into organisational functioning. Speaking of monitoring and evaluation, one respondent said: 'I have been trained, but I have never done it practically.'[50] Another noted, 'You will find that people workshop, workshop, workshop, and at the end of the day – nothing. …They just train individuals and at the end of the day, I am doing nothing.'[51] In the attempt to provide support for existing programmes, training is seen as an appropriate mechanism. However training needs to be complemented by institutional and infrastructural support, such as mentoring and support systems, which funders appear to be more reluctant to provide.

It is important to note that these issues pertain not only to private/external funders, but to government funding of community organisations as well. Ever-increasing HIV/AIDS budgets place stress on systems for planning and implementing programmes. Government funding is mostly ring-fenced for HIV/AIDS through the mechanism of conditional grants allocated to each of 11 specific areas of intervention as defined by a national comprehensive plan for prevention, care, treatment and support. Under this system it is not surprising that the more that resources are put into service delivery, the more need there is to develop management systems, to employ administrators, and to expand infrastructure. The ring-fenced funds are often not deployable for such purposes. To this extent, government – like external funders – undersupports those functions which are not directly connected to programme deliverables, but which are necessary to sustain and grow organisations.

[50] Co-ordinating body KZN
[51] Youth organisation KZN

Aversions to supplying core funding and the preference to augment programmes, rather than providing the means to sustain them, are a contributory factor to the strain that organisations face as they grow. Many organisations are in a state of perpetual crisis related to funding and an inordinate amount of management time is spent on sustaining the organisations from month to month, which detracts from their ability to engage more constructively with the programme development challenges they face.

5.4.2 Organisational focus: redirection to deal with a serious epidemic

There is ample evidence that perceptions of availability of AIDS funding have led community organisations to focus on HIV/AIDS more than they would otherwise have done. While such redirection is an important part of the HIV/AIDS response, and reprioritisation of activities is expected in the face of such a challenge, organisations that may have been established with a mission to address a certain set of issues – for example, local arts projects, or adult literacy – may, in the face of available financing for HIV/AIDS, introduce AIDS-related activities into their work or gradually shift the overall focus of their organisation.

There is a common perception that, although there is clearly community need and value in adding HIV/AIDS programmes to CBO programme portfolios, CBOs are also motivated by survival and self-interest needs. This was frequently linked to South Africa's high unemployment rates and to the difficulties that community organisations face in general in trying to mobilise resources. One result of this shift to incorporate HIV/AIDS programming is that organisations become inclined to tailor their activities to available funding opportunities.

In some cases HIV/AIDS funding changes the focus of organisations. Because funding for HIV/AIDS programmes is frequently obtained through specially developed proposals, it is often ring-fenced for specific uses. This means that organisations that are not specifically HIV/AIDS-oriented may regard their HIV/AIDS programme component as a separate entity, rather than as an extension of their initial programme focus. It is not uncommon that HIV/AIDS may begin to dominate the focus of community programmes and the focus on funded activities may absorb an organisation to the neglect of its non-funded activities.

There are clearly risks for organisations which move beyond their familiar areas of expertise and develop their organisations in unsustainable ways, but such shifts may be desirable to the extent that programmes mainstream HIV/AIDS into existing community development programmes.[52] For example, as one respondent noted, 'Others are just doing it, not necessarily because they aim to get funding. They are doing it because they believe that it's something that people have to talk about, like for example, these arts organisations, they don't go out and fundraise for HIV/AIDS programmes.'[53]

[52] Mainstreaming means embedding HIV/AIDS response in social assistance and development programmes, rather than regarding it as being the concern of specific HIV/AIDS organisations.
[53] Community rep EC

Some of these institutions that started off initially by doing a particular programme, you will find that now maybe 60 percent of what they are doing is based on HIV/AIDS. I do believe, honestly speaking, that it's all about the survival of those institutions and the availability of funds.[54]

There are organisations in the community that are only there because of the money.[55]

I think what I have realised is that you find people they are…they are in business. Because of pressure of HIV/AIDS, you find them they are concentrating on HIV/AIDS.[56]

I can tell you that most of them, those that are running the HIV/AIDS programmes… they are always trying to get money very quick. So they know exactly that the money for HIV/AIDS is there and it's just a matter of how to get it. I think that is the main thing and I think that is the problem of organisations, which is…how to get the funds. It's not how people can get the information of preventing this disease that they are concerned about.[57]

People tend to suit their product to fit whatever the funder is saying.[58]

They are also doing the trainings because they see that there is some funding for those who do some trainings.[59]

When a funder says I fund youth, I fund HIV orphans, I fund women who have households that are affected by HIV/AIDS, so people … will look and say, 'No, I don't even qualify in those things, okay'…and quickly they will cook up something that will make them qualify.[60]

You have your own programmes, then comes a funder that says to you, 'I will give you R1.5 million, but only if in your programme you include this and that and that.' Now we'll quickly change our programme to fit that of the funder, then the whole thing is changed. Its role is compromised and what we are doing then is just to have a mission statement that contradicts what we are doing because of that. It's easy to do that and I'm glad you asked that question.[61]

A certain organisation used to work hand in hand with the church to distribute soup and bread to the homeless – the people working in that organisation would not get paid to do that. But what happened when funding for HIV/AIDS arrived is that people stop providing those services and organisations started concentrating a lot on this funding. [62]

5.4.3 Volunteerism

A further concern under the rubric of 'additionality' is the erosion of the volunteer base of organisations. As organisations grow and become more substantial, volunteers increasingly expect to be remunerated for their services. This is transforming the culture of voluntarism in community associations.

[54] Community rep EC
[55] Community support org KZN
[56] Youth orgn KZN
[57] Community rep KZN
[58] Community co-ordination Gtng
[59] Youth organisation KZN
[60] Community rep EC
[61] Community rep EC
[62] Youth org EC

From the perspective of community volunteers, the provision of funding, especially when used for salaries of some members of the organisation, raises expectations of payment for all. When staff are paid and volunteers receive nothing, it raises the spectre of 'being used'. The expectation of some form of remuneration of volunteers in funded associations has become quite widespread.

The fact that some organisations, including government clinics, provide volunteers with a monthly stipend has entrenched this expectation. Differing practices related to remuneration, covering of expenses, per diems and so on for volunteers have created dissension to the point of volunteers accusing organisations of exploiting them. It also feeds into high levels of turnover among volunteers, who may either lose motivation or move on to paid work, should it become available. These are both consequences of funds being made available at local level.

The situation is not necessarily problematic and policy development and alignment around agreed-upon approaches to voluntarism would certainly assist to allay concerns that people are not being treated fairly against the benchmark set by other organisations. The provision of training and the acquisition of skills on the part of volunteers further change their motives. They begin to aspire to employment and career advancement. This may be of value in a context of growing need for local trained service providers, but it ultimately increases direct costs to organisations and places a large burden on management structures responsible for staff and for generating sufficient cash flow to meet monthly commitments.

> *It is not always easy as a Pastor to say to people, 'You must do this, do this because…you are available.' Sometimes people if they are doing voluntary work, they will sometimes need to be compensated. As I'm saying, funding is a major need because even though people understand what I preach and they are doing what I preach, but somewhere along the way I must compensate them for doing this work voluntarily.*[63]

5.4.4 Progress and challenges of additional funding

It is evident that there has been a great increase in the number of organisations responding to HIV/AIDS at community level and that some of this growth has been facilitated by an increase in the amount of funding available to support such activities. The research uncovered clear examples where the availability of external funding allowed community organisations to:

- Enlarge the scale and scope of their work
- Increase their professionalism
- Develop new capacities and skills in relation to project management.

There is little question that even relatively small injections of financial support into communities can contribute to significantly expanded outcomes. Apart from enabling expanded responses to HIV/AIDS, funding may also lead to other benefits, such as:

- Greater accountability (e.g. through reporting requirements and financial systems)

[63] Community support orgn KZN

- Improved skills in defining needs and project objectives
- Better understandings of how to undertake monitoring and evaluation.

To some degree, the receipt of external funding may help to validate the work being performed by organisations – and by the staff and volunteers who implement this work. In some cases, this may enhance both the accountability and local credibility of such organisations.

Yet the research has also identified a host of challenges associated with increased funding – some of which are unanticipated and which represent the 'underside' of the positive benefits noted above. These need to be addressed if the impact of funding is to be maximised and enjoyed more broadly:

- Additional funding often requires the development of management structures within organisations to deal with funding requirements and to address increased sustainability challenges. Where these do not exist, they place additional strain on organisations;
- Large-scale funding highlights the need for coordinating structures addressing multi-sectoral HIV/AIDS responses within municipalities and identifying where external support is most needed;
- New mechanisms for financing community-level work need to be developed to address disbursement of funds to various types of recipients. This should extend to levelling the ground for more equitable access to HIV/AIDS funds, with an appreciation for track record and prior experience, alignment with donor priorities, access to information and technology, familiarity with funding processes, and institutional connections of organisations;
- Striking a balance between funds allocated for HIV/AIDS response and principles such as community ownership of projects, particularly with respect to the integration of HIV/AIDS responses within a community.

5.5 Partnerships

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 with one another, and were linked up with government services, they could provide what would amount to a comprehensive and multi-sectoral HIV/AIDS programme with robust community participation. The purpose of co-ordination and partnerships is to avoid duplication, to identify gaps and needs, to build upon one another's abilities and skills, and in doing so, to maximise coverage. Of interest is the way in which the growth in HIV/AIDS response and increasing levels of funding for HIV/AIDS work may be leading or impeding partnership formation.

The community audit in 2003/2004 found that 88% of CBO/NGOs and 50% of FBOs network with other organisations, but that the number of formal partnerships (for example, service agreements or memoranda of understanding) was quite low – only 21% among CBOs/NGOs and none among FBOs. This finding is corroborated in interviews with community respondents

who confirm that contact between HIV/AIDS organisations is growing, even if this does not necessarily translate into local co-ordination of activities.

However, with the exception of an electoral ward-based co-ordinating body in one community, there is little indication of well-functioning co-ordination structures in the communities researched. Most organisations co-operate with a few organisations that they have immediate and practical need to have contact with, but such contacts are usually not formalised and are sporadic rather than regular.

This section looks in more detail at the relationships between community organisations responding to HIV/AIDS and other local actors and considers some of the factors which may contribute to or prevent effective partnerships.

> *So that thing has started to happen, but it has not been there before. It has never been there! Everybody was working in their own different directions and doing their own things. It's only now that it is starting.... I would definitely agree and say yes, there has been a lot of networking that has been happening.*[64]
>
> *We all meet together with organisations such as TAC, the Grahamstown Health Forum, organisations that deal with home-based care, with FAMSA, local clinics and so forth. We work together with these organisations and networking is there, because when there is a need for our assistance, we go there and we offer that organisation our help.*[65]
>
> *We don't have…a set programme of action that is known to everybody. So if you talk about coordination…it's not happening. If you talk about networking, then I would say yes, networking is there. But coordination so to speak in terms of it being a real…thing, rather than a dream by the organisations, then it's not happening like that.*[66]

5.5.1 Partnerships between community organisations

Interviews in the three communities explored the extent of partnerships between CBOs/NGOs at community level and the influence that HIV/AIDS funding may have upon the broader environment for partnerships. The number of practical partnerships between organisations is low, and a number of factors seem to work against their emergence – despite growing contact between organisations and despite frequently voiced realisations of the benefits that would come from closer cooperation and coordination of activities.

While the picture is not uniform, it appears that in many cases there is strong competition between community organisations working in the same field, and that this competition precludes a mutually supportive and collegial environment which recognises the strengths and contributions of different partners. Organisations do not seek to collaborate because they feel threatened by the successes of others and feel that their success in attracting funds means that they must stand out above other local organisations. Respondents spoke about envy between organisations, with successes met by increased need to criticise and diminish praise for

[64] Community rep EC
[65] Youth organisation EC
[66] Community rep EC

achievements (for example, the tendency to judge others based on factors like academic qualifications, levels of training, and quality of services). The increasing availability of HIV/AIDS funding may be exacerbating this competition – particularly among established organisations – by 'raising the stakes' in the competition between individual organisations.

Participants mentioned that when they work with other organisations, and thus contribute to the success of such organisations, their contributions sometimes go unacknowledged. The credit goes to the other organisation and they have effectively contributed their own resources to the other organisation. Organisations tend not to share information about their plans, services and funding sources because of the competitiveness between them and job insecurity. Members of organisations fear that if they divulge information to outsiders, those outsiders may come in and take their 'businesses' or even take up their positions in the organisations.

There appears to be competition for clients and territory. Without co-ordination, CBOs may conduct similar services in the same area and compete for clients. This is problematic when their performance is measured by numbers of clients using services or number of services delivered. Organisations feel threatened when new organisations emerge, perhaps introduced by larger NGOs and even international NGOs not previously active in the area. CBOs feel that they should rather be supported to improve and extend their services: 'I'm not happy, because some other programmes that are being funded - it's a repetition.' [67]

CBOs are often driven by a leading individual and such individuals are identified with the organisations they start and support over the years. They are inclined to want to protect the interests of their organisation, sometimes at the expense of the greater good - for example, in the face of suggestions that they focus on a particular and more limited set of services.

As a background to all of this are strong and often personal convictions of people involved in CBOs of the need to respond to HIV/AIDS. The fact that people involved in community organisations are often directly affected by HIV/AIDS places considerable pressure on them to respond. In this context opportunism and self-enrichment are regarded with suspicion and tension emerges between the 'opportunities' offered by HIV/AIDS funding and the humanitarian, community-motivated and philanthropic motives for response. Such a backdrop provides a poor context for partnerships.

> *Networking is like this: when I network with you I've got nothing to do with your bank account, I've got nothing to do what is there. We need to give each other knowledge of working with the patient. I've tried this and that and that with this patient. I took her to the clinic like this and that, so how can we improve? So that's my understanding about networking.*
>
> *[Interviewer]: So according to you, networking is about sharing of information and certain resources. But what are the fears of the people that you trying to network with?*
>
> *They think you want to take over. I will remove them from being*

[67] Co-ordination body KZN

> *coordinators and then I become coordinator. My name will come top and the name of the person who started the organisation - you will go down. That's what they fear.*[68]

5.5.2 Partnerships between NGOs/CBOs and government

South African government departments, including the Department of Health and Department of Social Development in particular, use CBOs and NGOs as service delivery partners for a range of functions, including many which relate to HIV/AIDS. Service-level agreements are therefore one of the clearest examples of partnerships between community organisations and the government. The community audit found that 40% of the CBOs/NGOs surveyed receive some form of financial support from government sources, while none of the FBOs receive government funding.

Awareness of the availability of funding from government departments was high among respondents, and some of the community organisations which receive funding from government sources expressed satisfaction with the support and assistance they receive from the government in the context of this funding relationship. Others, however, expressed frustration that the government doesn't expand and accelerate the allocation of support to NGOs and CBOs, particularly when it is known (or believed) that the government struggles to disburse the available funding: 'I think that our government is not consistent enough in utilising funds, because what is the use of drawing up a budget, a large budget, although you are not going to distribute all those funds?'[69]

Related to this is a certain degree of tension between government organisations and CBOs. There can be little doubt that many CBOs spend a large part of their time compensating for the weaknesses of the public health and welfare systems. It is not surprising, therefore, that they feel hostile to government employees who are paid for their work, whilst they commit their personal time and sometimes resources in volunteer work.

Apart from direct partnerships, another area of interface between community organisations and governments is in the realm of local planning and coordination around multi-sectoral AIDS response. The evidence from the research is not particularly encouraging in this respect, although in all three communities there has been some type of attempt to draw together actors for co-ordination purposes.

In the rural community, co-ordination of HIV/AIDS initiatives was found to be particularly poor. There are few permanent programmes in the area, although there have been a number of projects that have come and gone. Local co-ordination of more general community affairs is conducted by a tribal authority (chief), who has had relatively little involvement with HIV/AIDS projects. There is little linkage between community activities and democratic local government (a system of local governance which runs in parallel to the tribal authority), which is located more than 50 kilometres away by road and which has only a poor understanding of what is

[68] Community support organisation GP
[69] Community support orgn EC

happening in the area regarding HIV/AIDS. At least part of the reason for this is that the various government departments involved in HIV/AIDS (Health, Education and Social Development) are vertically decentralised and there is not much joint planning between these departments and local government, which is supposedly responsible for local co-ordination of community development.

Co-ordination at ward level is a strong feature in Vosloorus.[70] 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.

Moves are being made towards the formation of a Local AIDS Council in Grahamstown, which would likely supplant the HAST (HIV/AIDS/STI/TB) committee that meets on a monthly basis and 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 exact role of local government in relation to the emerging LAC remains unclear, although it is seen as critical that the LAC be located in the office of the mayor or municipal manager and receive the status of a municipal structure.

Overall, however, the research suggests that there is sometimes little formal involvement of relevant community-based organisations in planning new developments at local government level. There is no existing blueprint or published strategy for municipal-level HIV/AIDS responses and the official Integrated Development Plans of the respective municipalities are inadequate in their HIV/AIDS components. Lack of involvement of community organisations in working within government programmes is most notable in the case of the anti-retroviral programmes which are largely hospital-based and which community organisations have not as yet been formally drawn into, although they often supply much-needed background support in an informal and unrecognised way.[71] There are also often insufficient linkages between public sector institutions, such as clinics that provide VCT, and community organisations such as support groups, which provide on-going support to infected individuals in the community itself.

5.6 Sustainability

This section concerns itself with the extent to which external funding is leading to sustainable community-level responses to HIV/AIDS. Sustainability refers to the ability to function or operate over time without permanently damaging or depleting the resource base which facilitates those operations. In the case of community organisations, of interest is the extent to which an organisation's activities come to rely less on external sources as a result of more

[70] A ward in this context comprises a densely populated area of between 30,000 – 50,000 people.
[71] See Kelly & Mzizi. (2005).

predictable and diversified funding, better developed technical and institutional systems, and increased cost-efficiency. The following questions define the areas of concern: What is the impact of the funding environment on management efficiency? What is the alignment between funder priorities and the needs of CBOs which are servicing needs in communities? To what extent are organisations able to respond to the challenges they face and to upscale their efforts in keeping with the need for intensification at the level of scale, scope and rate of response?

The community audit conducted in 2003/4 captured information on the dozens of responses that are percolating up 'from below' and contributing to community mobilisation around AIDS in the three communities (see Section 4.2). This includes active engagement with HIV prevention and impact mitigation activities, and a growing role in supporting treatment programmes. However the survey also documented some of the organisational and developmental challenges being faced by such entities, including:

- Human resource management
- Development of monitoring and evaluation systems
- Resource mobilisation

If these organic responses are to become more orderly and more systematised – and if they are to be sustainable over time, beyond individual project trajectories – the developmental and support needs of community organisations need to be addressed.

The interviews with community-level respondents revealed many of the same concerns identified in the audit. Day-to-day concerns related to the survival of the organisation seem to take priority over longer-term developmental work. This may be reinforced by the tendency for external funding to focus on supporting programmatic activities first and foremost, rather than on building the infrastructural capacity of an organisation to operate successfully over the longer term. Pressure to fundraise and to cover direct costs leaves many organisations focused on the short-term rather than on building for the future. Management time is heavily invested in fundraising.

In the interviews, several areas of need were cited in relation to longer-term sustainability. These include:

- Capacity building and training within the organisation, including training of staff and volunteers;
- Training in monitoring and evaluation skills;
- Office space and infrastructure (including telephone lines) from which to manage growing operations;
- Building linkages between organisations.

5.6.1 Securing funding for staff

Funding for staffing is problematic for many organisations. Lack of ability to pay salaries or stipends means that many organisations providing services directly in the community rely almost entirely upon volunteers. This has implications in terms of human resources turnover (volunteers who are able to find paid work are likely to take the opportunity – see box below) and a failure to build longer-term capacity and skills within an organisation.

A number of respondents noted that organisations that have experienced success in attracting funds come under pressure to sustain the same level of funding so as not to cut back on programmes or staff. Organisations easily grow with funding, but they can't as readily shrink back to size over lean periods. There are considerable risks attached to employment of staff on a salaried basis. The challenge of meeting ever-increasing funding needs to sustain growing organisations consumes management time. With management preoccupied with organisational survival, the emphasis shifts away from developing programmes and delivering services. 'Now it's no longer about servicing the community and HIV affecting and infecting the people, it's about us, it's about the institution. It's no longer about the people outside there - no, it's about us inside the institution.'[72]

When staff need to be laid off, resulting conflicts about who retains jobs may result in severe distraction from the primary organisational objectives. At least in one case, this has led to chronic and unresolved interpersonal conflicts which consume an inordinate amount of time. Accusations of favouritism and formation of cliques around such issues have severely handicapped this organisation. The problem may be traced back to short-sighted employment of people without adequate long-term funding security. It seems that this is a risk for most community organisations where funding sources are tenuous at best.

> *It was our day to have our AIDS Forum meeting with the volunteers. The slot of that day was the impact of HIV/AIDS in the family…. Our secretary read the previous minutes. Instead of adopting the minutes, people started grumbling. They said: 'We can't go further with this every day. We always come with suggestions, but nothing happens. We work with the community, we always get sick people, but we can't help them because we haven't got materials, we always refer the clients to NGOs and the clinic. When are we going to do it for ourselves? Now is the time we step down.' I've tried to talk to them, but all was in vain. Four members of the Forum, plus most of the volunteers, resigned saying they are going to work with the funded NGOs.* [73]

5.6.2 Systemic needs

In speaking about priority areas for bringing about a sustained response to AIDS, a number of interviewees cited infrastructural and 'systemic' needs that at present do not appear to be priority areas for funders. These included commitments to developing functional Local AIDS Councils that could help to co-ordinate and integrate work at community level, community-based facilities such as 'day care centres' for HIV-positive individuals, and multi-purpose

[72] Community rep EC
[73] Diary exercise GP

centres that could integrate prevention, counseling, testing, support and treatment functions in one location.

Better integrated services lead to more focused services with better clarification of roles. Yet funders prioritise end-point services rather than process-oriented commitments such as management time, much of which is spent creating better co-ordination in a context of organic and unsystematic growth of organisations and activities. As a result, the development of systems and models takes second place to the imperatives of short-term service delivery. Were there to be better co-ordination at a community-wide level, activities of project staff could be more focused on service delivery.

Funder preference for key services rather than background developmental work may be linked to a continuing propensity for shorter-term unlinked project funding, rather than support for integrated programmes that build capacity within sectors of response. Further research into this will need to be conducted if the emerging trend away from project models towards broader programme funding becomes more pronounced.

5.6.3 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. The effective and considered management of these human resources has enormous implications for the sustainability of AIDS response over time.

In the community audit, 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.

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.

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 NGOs and CBOs 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, porous. 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.

Development of adequate human resource management frameworks is therefore important for sustainability, but is also very time consuming. To illustrate, many organisations try to have training accredited through the relevant SETA (Sector Education and Training Authority), which is responsible for developing training capacity and accreditation systems in almost all areas of public service and industry. In this way they hope to build up their volunteer base into a skilled service delivery workforce.

The sustainability of community-level action requires more than the back-up of a well-functioning organisation. The human capital engaged in community-level HIV/AIDS support is strongly subject to erosion through burnout.[74] This results in staff turnover and conflict within organisations under pressure to deliver services in an area where there is high need, inadequate co-ordination, rapid organisational growth and insecurity about organisational survival over the long term. Counteraction requires external intervention in the form of human resource consultants, conflict-management specialists, stress management training and organisational development interventions, amongst others.

The areas of management skills deficit that are most notable are funding management, proposal writing, financial management, project design and conceptualisation, information management, and monitoring and evaluation. Although undocumented, it is very evident when briefings are held around calls for proposals, that there is a coterie of management-type organisations clustering around HIV/AIDS programmes in the interest of providing such services. There certainly is work for them – there is a high reliance on external technical assistance for such basic management activities – and it seems that funders are willing to pay for such external forms of assistance. Such interventions are hopefully of value and may lead to greater capacity of organisations to develop in sustainable ways. However, inputs in these areas are unlikely to reverse the fact that CBOs working in HIV/AIDS in this context are likely to be chronically dependent on external funding and such funding needs to cover basic costs as well as service costs.

> *I think the problem is with the SETA. For example… in the past two or three years we were training our volunteers in home-based care and in*

[74] Raviola et al. (2002) discuss this with reference to 'burnout'

> *HIV/AIDS awareness raising education, then that course we started with an institution in Cape Town and it was the SETA that was going to accredit it. But we found out that if they ask for this one document, then they will ask for another one. When you have sent them those, then again they will ask for another one. So it was that long process. I think when it comes to documentation, then the process becomes too complicated for us.*[75]
>
> *We have to provide HIV/AIDS services on top of what we have been doing. That has put enormous pressure on the workforce…from 2003 and in 2004 …all nurses, professional nurses including the counsellors had to see psychologists themselves. Yes…because that has really taken a toll on them, you know, coping with the patients and coping with the disease itself, the clients plus the overwork, ja. That has put a lot of pressure and in turn, if they are pressurised down there, then definitely that comes back to the office.*[76]

5.6.4 Co-funding

A further challenge with respect to sustainability arises from co-funding arrangements. Although government funding is problematic because of its unpredictability and frequent delays in disbursement, some organisations that meet the reporting requirements appear to be able to secure relatively sustained funding commitments. Other sources of funding, however, are usually project bound and may involve various requirements which, in subtle ways, undermine the long term sustainability of organisations.

Amongst these requirements, perhaps the most important is that projects should become increasingly less reliant on a particular donor's funds, and that funding streams should be diversified across various provincial, national and even international sources. Whereas this may be appropriate for relatively well-functioning organisations with skills to secure additional funds, most CBOs do not have such capacity. Yet they are able to conduct simple tasks such as house visits, or training for home gardening. They need sustained, single sources of funding, but large-scale funding programmes and small-scale external funding programmes are not geared for providing such support. There appears to be a problematic assumption that small community-based organisations servicing HIV/AIDS needs can at some point in the future become self-sustaining. But in the absence of user fees, which are not viable in the poverty-ridden contexts of AIDS support, and based only on the efforts of a few struggling volunteers, many such organisations are unlikely to be sustained.

Another effect of the counterpart funding requirement is that the overall funding base becomes increasingly 'fragmented' as it is drawn upon by multiple organisations all seeking to secure counterpart funding. This process, in addition to being unwieldy, increasingly consumes management time.

[75] Community support orgn EC
[76] Co-ordinating body EC

5.7 Accountability

This section addresses issues of accountability related to HIV/AIDS funding, including monitoring and evaluating the impact of funding disbursements, as well as the use of these funds in accordance with declared objectives. With general agreement on the part of funders on the need to invest in development of monitoring and evaluation (M&E) systems,[77] it is apt to consider the extent to which M&E is developing as part of community organisation operations. It is an implicit requirement of most large-scale funding programmes that funded organisations report on their outputs using appropriate indicators and systems of data gathering and management.

Accountability is important in a broader sense as well, as it relates to perceptions within the community that funding being allocated for HIV/AIDS activities is being spent wisely and is being handled honestly and transparently. As one respondent said,

> *I don't have a formula but I think people are just… wanting money to be spent. Everybody is just saying, the government can't have all this money left in their pockets, they should have spent that money, right? Now, is it for the real cause, honestly speaking, or is it just being spent for the sake of being spent? There are programmes that are very good, that are actually spending money on HIV/AIDS really wisely. … There are organisations, private organisations that feel they have a social obligation to give people funds and they will look around for an organisation that they know in the Makana area and they will give them money. Is that money wisely spent or is that money given just for the sake of being given out to people?*[78]

5.7.1 Capacity for M&E

Respondents were generally cognisant and supportive of the need for monitoring and evaluation skills:

> *We need evaluation skills to see…to measure ourselves and to see where we are going and what have we done so far. … And other CBOs, NGOs and any other structure must have evaluation skills, even the government must have a form of evaluation. …They say they are able to fund a CBO in a place like this, then they must be able to come and see what we have done, what was the impact there?*[79]

However, the interviews and the community organisational surveys found very mixed levels of capacity at community level to conduct basic M&E. Understandings of M&E seem to vary widely: several organisations noted that M&E involved them receiving 'feedback' from community members. Others suggested that M&E has been 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.'

In the survey of community HIV/AIDS organisations, it was apparent that the growth of awareness of the need for M&E was largely related to funders increasingly demanding to know

[77] UNAIDS. (2004b). *The 'Three Ones': Driving concerted action on AIDS at country level*. Geneva, UNAIDS.
[78] Community rep EC
[79] Youth organisation KZN

the outcomes of programmes, and requiring organisations to account for what has been achieved. At programme level this ideally requires systematic monitoring of activities and outputs and the use of information management systems. While some of the more established organisations have incorporated evaluation activities into their work on an on-going basis, and while familiarity with the *concept* of M&E appears high, the overall level of M&E capacity seems to be quite low. This can be seen in the findings from the community survey, presented in Table 5 below.

Table 5: Monitoring and evaluation activity among community organisations (%)

Type of M&E	CBOs / NGOs	FBOs	Comment
Monitor the number of clients using services	65	44	A sizeable percentage of organisations do not keep records on the number of clients served. This makes it difficult to quantify changing patterns of demand and use of services over time – a basic indicator for assessing an organisation's reach and critical information for planning purposes
Monitor number of items distributed (e.g. educational materials, condoms, etc.)	65	38	Where distribution of items is not tracked, there is an absence of reliable information about patterns of demand for various materials which would be useful for planning purposes.
Monitor programme performance and deadlines	74	38	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 voluntary counselling and testing – 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.
Programme activities have been evaluated	58	25	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. 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.

Monitoring and evaluation seems to be highly valued in theory, even if it is not widely undertaken in practice. For those interviewees that are involved in provision of services, there is a strong recognition that M&E is valuable for obtaining further funding. One organisation linked M&E to the accreditation it received from a national body. One programme showed a particularly keen awareness of the internal value of evaluative practices. However, apart from this, there was generally relatively little value attached to the role of M&E in programme management and development.

> *We are now in the process of evaluating the HIV/AIDS skills training programme, whether it was successful or not...with those participants who took part in our training. But we do monitor and evaluate the programmes… maybe two times in a year we hold some action-reflection meetings where we invite the members of the action group to come under one roof here in Grahamstown, where they can identify the challenges they are facing, their achievements and what the stumbling blocks are in*

> *implementing the programme itself.* [80]
>
> *Organisations…don't keep track of what is happening. They just live day in and day out to see if they can set their foot at the right place on a daily basis, which is a sad thing because organisations should be planning six or ten months ahead for what they want to do the following year.*[81]

5.7.2 Challenges to M&E

Among challenges cited, organisations noted a 'lack of co-operation' 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. The process of monitoring requires systematisation of data collection as an intrinsic part of programme operations; capturing, analysing and presenting such information; and ideally use of this data in reporting and programme development. A break in this chain of activities results in overall failure. It is not surprising then that programme staff say that they collect information in the field, but that they struggle to produce quarterly programme reports because they do not have access to the information in a readily useable form.

Clearly the need and expectation that CBOs monitor their outputs, and that funders receive reports on what has been achieved with funding, is well-founded. But the capacity to conduct M&E and the costs of M&E are prohibitive. This is especially so for smaller CBOs. It seems that those organisations that are supported through a few rounds of funding and reporting are able to meet requirements, as was the case of one organisation that initially struggled, but eventually developed a good working relationship with the funder, which was a provincial Department of Health. Where there are multiple small funders, and where posts and services are funded by multiple sources, the challenges are more daunting. There appear to be few organisations working to support CBOs in developing M&E capacity, and it would clearly serve funder interests to support CBO capacity-building organisations to work in this area. Mentoring relationships between support organisations over a period of time would be most appropriate.

5.7.3 M&E and accountability

It was apparent in interviews that M&E is seen as a very important way of guarding against improper use of funds. Reasons given suggest quite high levels of suspicion within communities that project money is abused and doubts about the efficacy of small community projects. There is strong support for the idea of monitoring, on the back of the perception that funders may be unaware of the extent to which community funds get displaced to uses which are not directly attached to programme objectives. Strong opinions were expressed that funders should be more concerned about monitoring than they currently seem to be (see box).

The need for funders to be vigilant about how funds are spent is heightened in the minds of respondents by concerns about business interests and personal enrichment that are sometimes

[80] Community support orgn EC
[81] Community rep EC

associated with HIV/AIDS initiatives, and concerns about 'corruption'. Respondents reported that organisations do not necessarily follow what they originally proposed to do, but that funders are often not aware of this if they don't have in place adequate mechanisms for monitoring. This is especially apparent as a problem in smaller organisations where there are only very modest sums of money involved and where less rigorous monitoring is likely to be required.

Such calls for external monitoring should be cause for concern, as they reflect the perceptions of people knowledgeable about the functioning of CBOs, and pose troubling questions about the efficient and appropriate use of funds by CBOs.

> *You cannot know a person if you are far away from that person. I am still saying there are organisations in the community that are only there because of money. But you may not even know them if you don't come talk to them.*[82]
>
> *They [funders] should leave their offices… if they do the fieldwork that is where they will find different organisations who are after money and who are after the improvement of people's lives. Then they will be able to differentiate that we can work with this one or this one is just after money, so we will not work with this one.*[83]
>
> *Funding these organisations is useless, you see, not unless the funder conducts a follow up to find out how those funds are being utilised.*[84]
>
> *Organisations should be viewed according to their merits. Someone should come and assess those organisations first, then give them the money that they think that they deserve in order to do the work that they need to do. Even if they are doing a programme on gardening to support people who are HIV positive, there should be somebody there who is going to go to those places where they say they own pieces of land to see what they need in terms of the apparatus and the equipment, and the food that they want to produce, without necessarily giving them money. You can do that very easily.*[85]
>
> *Let me say, for example, our organisation got funding. Then at the end I say, 'Remember, I am the one who came with this idea to have this NGO and to have this money, so this money belongs to me.' And this time around, so many people come into the picture - like this is my sister, this is whoever, whoever. You see, something like that. So the organisation is no longer running smoothly, so they have fights within themselves, within this NGO. Yah, because they do not use funding appropriately, you see.*[86]
>
> *Even the funder who is funding that organisation should do monitoring and evaluation. Does that organisation that's being funded do exactly what they proposed to before they got that funding? Because I can do the proposal to the funders, that I'm going to do 1, 2, 3, 4, 5 in the community, and then I will get the funding but nobody is visiting me to see whether I'm doing the right thing as I proposed to you to get the funding.*[87]
>
> *The programme itself should be able to say right from the beginning that there will be measurables along the way to say, how is this programme that we are doing going to be effective. Right? But do funders check for that honestly speaking? …When you go to them and you say we are going to be doing this and this for five years, do they check if this programme is going to be really effective, or is it about the number of*

[82] Community support orgn KZN
[83] Community support orgn KZN
[84] Youth orgn EC
[85] Community rep EC Rnd
[86] Co-ordinating body GP
[87] Co-ordinating body KZN

> *people that you say you are going to service in your programme? Is it about 400 orphans, or is it about 10 orphans that are going to be well cared for, that are going to be taken from the misery that they are in and be made real citizens of this country, just ten of them?*[88]

6. Discussion

6.1 Opportunities and challenges

There is growing evidence of broad-based social mobilisation around HIV/AIDS in South Africa. The research conducted by CADRE in Vosloorus, Obanjeni and Grahamstown between 2003 and 2005 has uncovered strong growth in the number of community organisations involved in various aspects of HIV/AIDS response. Although community-level activity around HIV/AIDS has still not been studied in a systematic way in South Africa, a growing body of anecdotal information and localised studies corroborate the findings from these three communities.

It is clear that community-based organisations have alighted to the possibilities of taking roles in providing basic services related to HIV/AIDS prevention, care and treatment. In some cases they are doing so as officially outsourced service providers for government, while in other cases they provide services on a purely volunteer basis or with the support of resources mobilised in the community or from donor institutions. Community-based organisations appear to be playing a particularly strong role in impact mitigation activities, including care and support to orphans and vulnerable children, home-based care, support groups, and individual and family counselling. They are increasingly becoming involved in eligibility assessments for ART, treatment adherence activities, and nutrition education in support of ART. As organisations with direct and on-going contact with HIV-positive clients, they also play an important role in making the social and health service systems work in contexts of inadequate local implementation systems and infrastructure development.

Despite this upsurge in activity, community organisations involved with HIV/AIDS response face a set of significant challenges that affect both their daily operations and their longer term growth and sustainability. These include:

- ***Chronic challenges in securing funding*.** Many of the community organisations interviewed for this research have had little or no success in accessing funding in support of their work, and carry out activities using volunteer labour and donated goods. The community audit found that nearly half of respondent organisations in the three communities cited funding as their main organisational challenge. Funding is difficult to access for groups that are newly established, lack a programmatic and financial track record, and are not networked into structures that might alert them to opportunities for accessing small-scale start-up funding. A transparent proposal process with appropriate feedback to organisations is required, with the burden placed on financing agencies to provide this.

[88] Community rep EC

- ***Inadequate human resource capacity and skills base***. Many organisations providing services in the community rely heavily upon volunteers who are unpaid, or receive only small stipends. Turnover rates among volunteers tend to be high, as they may be lured away by the opportunity to undertake paid work or to receive a larger stipend at a different organisation. While both voluntary and compensated staff models provide different advantages, it is uncertain whether one or a combination of models is more sustainable for scaling-up services. Further investigation is required in this area. Levels of training and skill among volunteers and staff vary widely. The HIV/AIDS field is developing rapidly and it is critical that human resource capacity keep up with changes in the sector. In most local organisations there are inadequate human resource systems and insufficient attention to the professional development and career pathways of volunteers and staff.

- ***Limited familiarity with monitoring and evaluation processes***. Monitoring and evaluation techniques that could assist community organisations to plan their programmes, document their work, and begin to position themselves strategically within the sector do not appear to be widespread. While basic monitoring is within the reach of many community-based organisations (such as simple measures of people reached), limitations exist in capturing more complicated measures. Additionally, moving from monitoring to evaluation presents challenges for organisations operating with limited capacity. Monitoring and evaluation is seen as a funder-driven requirement, rather than a practical tool for improving organisational performance. Within organisations that are over-committed and under-resourced, monitoring and evaluation is not seen as a priority, and understandings and capacities in relation to it are limited.

- ***Insufficient linkages between organisations and other actors involved with AIDS response***. Although there is evidence of increasing networking between AIDS service organisations, this does not yet appear to have reached the level of systematic co-ordination. Competition at local level – for resources, territory, and clients – may be impeding the emergence of partnerships, but so too is the absence of community-based forums where such partnerships might be forged. Most contacts between organisations seem to emerge in an ad hoc way, on the basis of need or within a particular sector of response. However this has not yet translated into a more organised set of service-oriented alignments that would allow for local strengths to be built upon, gaps to be filled, and duplication of efforts to be reduced.

6.2 The role of funding

Many of these challenges could be addressed through process-oriented investments in systems development, organisational development, and human resource management systems, among others. While some donors are beginning to prioritise these areas, at present they remain underdeveloped in the South African context. On the whole, the given research has found little indication that community organisations are becoming more sustainable – in fact, the opposite may be the case as small organisations invest increasing time and effort in simply keeping their operations running, funding staff salaries and volunteer stipends, and meeting reporting commitments. While there are certainly examples where organisations have become firmly

established and have developed solid programmatic track records, these appear to be the exceptional cases, rather than the rule.

The current local level HIV/AIDS response environment is characterised as much by conflict as it is by co-operation and integration of activities. There are signs that the relatively greater availability of funds for HIV/AIDS is increasingly leading organisations to orient around HIV/AIDS, providing a much needed response to the HIV/AIDS challenge. However, this re-orientation may be leading to the neglect of other social needs and to high coverage by low-grade and inexpert programmes that are oriented around short-term funding and one-off interventions. The research also uncovered surprisingly frequent expressions of suspicion about the efficacy of AIDS response work being conducted at community level and about the processes by which AIDS funding is allocated to organisations at local level.

The above shows more challenges than we expected, given the promising evidence of community mobilisation, and shows us that there is much work to be done in laying the foundations for more systematic, efficient and sustained local responses. It is not surprising that a chaotic and underdeveloped situation prevails as there is almost no policy and strategy in South Africa related to the development of local responses to HIV/AIDS. This is partly because health is planned and delivered at the provincial level and links between local health service areas falling under provinces and local government and communities are weak. As a result, a systems-based approach is needed to optimise the effectiveness of community organisations.

6.3 The need for coordination around local-level AIDS response funding

In South Africa local government is mandated to oversee and co-ordinate local development planning and management. As part of this function, local and district-level municipalities are encouraged to form AIDS councils. These are not currently of much practical value, although in some provinces provincial HIV/AIDS funds are being channelled to district level where they are committed to projects and organisations which are contracted through service level agreements. There are many unmet challenges in this area. Success requires the development of capacity for forming and managing partnerships with local organisations, and development of systems for monitoring the use of funds and systematically developing integrated systems of response at the district and municipal level. It is in keeping with the mandates of local government in South Africa that this should happen, but local government is currently the weakest link in governance and much work needs to be done to develop systems and train personnel for such tasks.

There is a strong need to develop strategies around co-ordination of local-level response funding. There has been remarkably little work in this area and an inconsistent approach prevails. Whereas the National Department of Health has a funding matrix which periodically gathers data from the larger bilateral and multilateral donors, there is no equivalent for

internally funded efforts or other funding agencies. In many cases it is also difficult to track the actual flows of funding down to community level, as it may often be passed through one or more conduit organisations. It is therefore important for provincial and local level co-ordination mechanisms to develop. Funders are not generally in a position to know who is doing what in a particular area and what is and isn't needed. If local government is not in a position to facilitate better co-ordination in respect of funding, then it is important that provincial-level NGOs be supported to take on the function of managing funding proposals and acting as a conduit for external funds.

The most significant problem in this regard lies in developing and managing partnerships with community organisations, which are often able to provide needed services, but which are not able to meet requirements of fundability, such as possession of financial and information management capabilities. Accessing small-scale 'start-up' funding is a particular challenge. Throughout the country there are capacity-building organisations which focus on developing community organisations. Some of these are adopting a role in relation to funding, acting as funding conduits or assisting local organisations to access funds in partnership with other organisations, or simply by assisting them technically to fulfil criteria for fundability and to prepare documentation and proposals.

Scaling up the fight against HIV/AIDS must address the problems identified in this report, ranging from the suggestion of one small organisation – 'One of the things is to simplify the registration of forms that are used to apply for funding'[89] – to developing systems for monitoring the impact of large-scale funding programmes implemented at local level. The solution cannot be to give the money to government, as government is itself increasingly looking for partnerships with civil society in implementing and supporting programmes at local level. A closer-to-the ground approach is required that draws upon existing coalitions, capacity building organisations and coordinating bodies. These organisations should be enlisted in developing more co-ordinated and broader-based strategies for local level funding.

A number of models do exist that appear promising in terms of addressing these challenges:

Mentoring Approach: One model of remediation assists small organisations to become fundable in the first instance by pairing them with well-functioning mentor organisations that assist them to develop appropriate systems for receiving and managing funding, keeping records and reporting, and planning.[90] Seed funding is paired with on-going organisational development support. This has been successfully implemented some sites in South Africa and the results look promising, although the process is extremely labour intensive.

Umbrella Approach: A similar approach is to scale up the use of umbrella organisations – well-established NGOs that can serve as conduits for channelling funds to smaller groups. Donors effectively liaise with one recipient organisation – the umbrella group – but the funding

[89] Youth orgn KZN Rnd2.txt
[90] Magongo et al. 2004b

itself is dispersed more broadly. Management of the sub-grants, including monitoring and reporting requirements, are the responsibility of the primary recipient, but capacity-building components are built into the agreements so that end-recipient organisations gain experience accounting for funding and reporting on results. These types of funding arrangements are not uncommon in South Africa, but could be utilised more widely with the goal of channelling a greater proportion of funds to the grassroots and building local capacity to absorb funding.

Networks and Coalitions: Another approach is to channel funding for community HIV/AIDS response through co-ordinating coalitions of HIV/AIDS organisations, where these exist, and to allow these coalitions to allocate the funds from a common 'pot' to locally determined priorities. In cases where there is a multi-sectoral coalition that is seen to credibly represent the interests of most local HIV/AIDS organisations, it makes sense to further empower such entities by allowing them to apply for and receive funding on behalf of the community's AIDS response actors as a whole.

Such groups have a better sense of local needs and capacities than do external funders and are well positioned to get funds to where they are needed without the risks that have been highlighted above. At present, there are few known examples of coalitions in South Africa that are ready to operate in this manner – although the CINDI network in Pietermaritzburg is an innovative model that should be closely studied. As movements towards local integration and coordination of HIV/AIDS response increase, this approach may become more viable and should be encouraged by donors.

Community focal points: Lastly, the presence of community focal points to co-ordinate activities at the community level, as well as liaise with provincial and national departments of health, may present a viable option to help address some of the challenges raised in this study. A community focal point, independent of funding bodies, can play a brokering role, facilitating co-ordination from funding proposals to service provision.

6.4 Key recommendations

There is a great need for increased funding for HIV/AIDS response to reach structures working at community level. In the case of HIV/AIDS, the urgent large-scale roll-out of interventions has necessitated that many effects on community systems have been overlooked in the aim of reaching more people with essential services in short time spans. In the realm of finite resources to fight the HIV/AIDS epidemic, these resources must be efficient and practically used for the communities who need them to appreciate their full benefit.

Ensuring the optimal and efficient use of HIV/AIDS financing is a shared responsibility between donor agencies and national governments. Key findings from this work suggest that there are many systems effects typically observed at the community level that escape national-level analyses. Concerted effort need to be placed to ensure that financing is equitable, additional,

sustainable, contributes to useful partnership development, and makes its way efficiently from international and national levels to community and local level initiatives.

Despite clear progress in the growth of organisations and financing at the community level, community level responses to HIV/AIDS financing as evidenced by this study clearly indicate that much work still remains to ensure HIV/AIDS funding meets important criteria to minimise systems effects. At the broader level, much effort needs to be made to ensure:

- Attention to developing integrated systems of HIV/AIDS response at the district and municipal level, including the formation of policy and a strategy for capacitating local actors to adapt the policy to local conditions
- Commitment by donors and government to steadily increase the proportion of HIV/AIDS funding that reaches organisations at the grassroots level
- Investment in funding models – such as conduit organisations and funding of HIV/AIDS coalitions – which can help to channel funds to local organisations, including seed funding for newly established groups

Importantly, the development of a community systems approach can optimise the efficiency of organisations, maximising the community-based response. This involves:

- Greater emphasis on the part of donors on funding the development of various systems, including organisational development and human resource management systems at organisational level, and Local AIDS Councils and other co-ordinating bodies at community level
- Developing systems for coordinating and monitoring funding for local-level responses
- Enhancing the role of NGO/CBO capacity-building institutions in relation to the development of local-level AIDS service organisations
- Investigating and taking steps to address the extent to which HIV/AIDS funding is altering organisational mandates and leading to a reduction in attention to other social needs
- Redoubling of efforts to make funding allocation processes transparent at community level
- On-going attention to monitoring and measuring systems effects of large-scale funding at local level

References

Birdsall, K. (2005). *Faith-based responses to HIV/AIDS in South Africa: An analysis of the activities of faith-based organisations listed in the National HIV/AIDS Database*. Johannesburg, CADRE/HIVAN. www.cadre.org.za.

Birdsall, K. & Kelly, K. (2005). *Community responses to HIV/AIDS: An audit of AIDS-related activity in three South African communities*. Johannesburg, CADRE. www.cadre.org.za.

Dorrington, R., Bradshaw, D., Johnson, L. & Budlender, D. (2004). *The demographic impact of HIV/AIDS in South Africa. National indicators for 2004.* Cape Town, Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.

Foster, G. (2002). *Understanding community responses to the situation of children affected by AIDS: Lessons for external agencies*. Draft paper for the UNRISD project HIV/AIDS and Development. Geneva, UNRISD.

Guthrie, G. & Hickey, A. eds. (2004). *Funding the fight: Budgeting for HIV and AIDS in developing countries.* Cape Town, IDASA AIDS Budget Unit. www.idasa.org.za.

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

Magongo, B., Parker, W., Kelly, K. (2004a). *Addressing the challenges of funding local responses – Case study from South Africa*. International AIDS Conference, Bangkok, Thailand. Poster presentation. www.cadre.org.za

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

National Department of Health. (2004). *National HIV and syphilis antenatal sero-prevalence survey in South Africa 2004*. Pretoria, Department of Health.

Ndlovu, N. (2005a). *An exploratory analysis of AIDS donor funding in South Africa*. Budget Brief 155. Cape Town, IDASA AIDS Budget Unit. www.idasa.org.za

Ndlovu, N. (2005b). *HIV and AIDS allocations: A first look at budget 2005*. Budget Brief 152. Cape Town, IDASA AIDS Budget Unit. www.idasa.org.za

Shisana, O. et al. (2002). *Nelson Mandela/ HSRC Study of HIV/AIDS. South African National HIV Prevalence, Behavioural Risk and Mass Media. Household Survey 2002*. Cape Town, Human Sciences Research Council.

Statistics South Africa. *Population Census 2001*. Pretoria, Statistics South Africa.

Raviola, G., Machoki, M., Mwaikambo, E., & Good, M. (2002). HIV, disease plague, demoralization and 'burnout': Resident experience of the medical profession in Nairobi, Kenya. *Journal of Culture, Medicine and Psychiatry*, 26 (1), pp. 55-86.

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

UNAIDS. (2004a). *Funding for AIDS – Factsheet*. Geneva, UNAIDS.

UNAIDS. (2004b). *The 'Three Ones': Driving concerted action on AIDS at country level*. Geneva, UNAIDS. www.unaids.org.

UNAIDS. (2004c). *Report on the global AIDS epidemic.* Geneva, UNAIDS.

UNAIDS/OECD. (2004). *Analysis of aid in support of HIV/AIDS control*. Geneva, UNAIDS.

Appendix 1: Individual responses to AIDS

The youth behavioural surveillance survey conducted in the three communities in April 2004 provides some insight into individual responses to the epidemic.

- One of the major factors influencing behavioural responses to HIV/AIDS appears to be personal knowledge of people who are HIV-positive, have AIDS, or who have died of AIDS. In the youth survey 60% of respondents reported that they currently knew somebody who is HIV positive (2004).
- Not only is HIV/AIDS making its presence felt, but young people are also communicating about it. In the behavioural surveillance survey only 3% indicated that they would keep their status a secret if they found out that they were HIV positive.
- There are indications that HIV/AIDS is fairly openly and frequently discussed amongst young people. Asked as to who they had discussions with about HIV/AIDS in the last three months, youth respondents reported: close friends (55%), mothers or fathers (34%), partners (30%), and religious leaders or colleagues (8%).
- Of the participants who had sex before (87%), 86% percent had used a condom at some point before and 63% used a condom the last time they had sex.
- When asked about their knowledge of where to go for an HIV test, 71% of the participants knew where to go, although only 29% of the participants had undergone an HIV test.

It was apparent in interviews conducted specifically for the current report that many community members are deeply affected by the physical and emotional pain experienced by people with AIDS and their family members. Direct encounters with people with AIDS – including close friends, family members, and respected members of the community – lead people to realise that it is not a disease that affects 'others' or certain profiles of people. Respondents noted becoming 'more serious' about life, changing sexual behaviour patterns to minimise risk, and deciding not to compromise on personal well-being and safety as a result of their own personal exposure to people infected or affected by HIV/AIDS.

Responses to HIV/AIDS also appear to be motivated by broader reflections on the impact of the epidemic on society and the fact that 'stakeholders in society' have failed to act, leaving the onus on community members to do something. One respondent noted that the social dimension of the problem is becoming more and more apparent as a growing number of people are dying and children are being left to fend for themselves. These reflections are linked to a sense of responsibility – or 'calling,' in some cases – to become involved at community level.

Interviewees were asked to comment upon funerals they have attended of people who have died of AIDS and upon the degree of openness which prevailed at these funerals. Responses varied widely and covered a spectrum of behaviours and practices that ranged from open acknowledgement of AIDS as cause of death and deliberate use of funerals as a vehicle for

'public education,' to funerals where the deaths of known HIV-positive people are attributed to witchcraft or 'short illnesses' without recognising the role of AIDS.

The consent of the deceased's family to discuss the cause of death openly continues to be a decisive factor in terms of addressing AIDS at funerals. However the interviews suggest that other actors are emerging as powerful in this regard: caregivers, volunteers, members of support groups and PWA associations are often present at funerals of people who were openly HIV-positive, introducing symbols such as lit candles, ribbons and T-shirts into funeral proceedings. Although consent of the family to disclose remains critically important, respondents note that tributes made by friends and acquaintances can often contain indirect hints or veiled confirmation of the cause of death, thereby suggesting that the family's right to privacy is not always regarded as paramount.

Priests are not playing a uniform role in relation to treatment of HIV/AIDS at funerals. Different attitudes and behaviours were described by respondents. While some priests use funerals of all types – including those of people who did not die of AIDS – as opportunities for speaking about the importance of caring for oneself and leading a healthy life, others maintain that disclosure of AIDS as a cause of death is the prerogative of the family of the deceased rather than an issue for the church as an institution to decide on. Either way, it is apparent that there has been much public discourse around the ethics and value of acknowledging AIDS as a cause of death. South Africa has clearly reached a point where, politics aside, communities are well aware of the threat of HIV/AIDS and amply exposed to its realities.

Increasing access to treatment did not emerge in interviews as a factor which is influencing community-level attitudes and responses to AIDS. It was reported as commonly recognised that HIV-positive people experience an objective and subjective improvement in their physical health and psychological well-being once on ARV treatment. There were passing references to people who may think that the availability of treatment creates a context for people to continue with risky sexual behaviour or discontinue preventive measures. However, the impression is that, contrary to what is often supposed, the society is going through a profound reorientation leading steadily to an acceptance of HIV/AIDS as a reality which needs to be engaged with at an individual and collective level. Concurrent with and supportive of this context we have the emergence of more organised responses to HIV/AIDS at community level.

Community awareness and responsibility

Speakers are aware that it was HIV/AIDS and they will hint here and there by saying, 'You know, he started by having this and later this developed.' And again and again they will mention the diarrhoea and that he was losing weight and all that….The awareness rate is high, people know now what is happening and they are quite aware. Even if they won't say that he died of HIV/AIDS, but when they are talking you will hear the speakers hinting at it.[91]

We have been involved with people from NAPWA in Durban, and they come and address the people who are there at the funeral. And we also have a support group and different support groups attend the funeral for Ngwelezane, Esikhawini, and all those places. They come to support their member and they wear those t-shirts and they give talks. And we even invite a community leader sometimes to say this person was open, to say he was living with HIV/AIDS. We have buried a number of people.[92]

I was at Katlehong at a funeral of a mother of two children. The mother was a client since 1995. She died of AIDS. The family wanted all the ward members, the NGOs, the volunteers to come together and make the HIV/AIDS awareness during the funeral. All these holders must wear their HIV/AIDS t-shirt [and there were] stickers to stick all the people that attended the funeral. To me it was a message of HIV/AIDS to the public. The family allowed the PWAs to talk about HIV/AIDS. So people see for themselves that you can live with HIV/AIDS as long you have a positive life.[93]

The suffering I that I have witnessed. I… I… it's unbelievable! It changed me to say, look, I do not want to see any other person…in that state again. And it happens that it hits, you know, in your own family and I watched my cousin's brother being wasted away and I couldn't believe that. A very strong person! …I watched him… and sometimes I didn't want to talk to him, not that I hated him, it's just that I…I couldn't stand the pain that he was in when he's about to talk. I mean, someone just getting tired from just talking to someone, then you feel, let me just let him rest – he can't even talk, you know.[94]

So, I don't drink and I am too aware of this thing, I am too scared of this thing so I don't compromise when it comes to using a condom, to such an extent that…I don't wish to meet a girl that does not have the same attitude as I do, which might lead us to disagree about a situation of this kind, you see. Because I don't ever want to infect somebody else and I don't want anybody to infect me either. So, what's happening to my sister and to my friend, that thing is making me take this whole issue very seriously. I am very serious now about my life.[95]

It's the dying of people and seeing ourselves and other stakeholders fail to stop the spread of HIV/AIDS to the community. That's why I was personally taking the responsibility of advocating.[96]

It's to see people dying, you know, people that I know and there are people around, living around me and to see them dying like this, like

[91] Co-ordinating body EC
[92] Youth organisation KZN
[93] Diary Exercise GP
[94] Global fund int EC
[95] Youth organisation EC
[96] Co-ordingating body KZN

flies, it hurts. It hurts a lot because they leave behind children that have nobody looking after them. There is a case in our area of children, there are four of them in that house and the eldest is round about fifteen years. So that is going to be a problem as time goes on because those children as they grow up will not know how to be loved, then they are going to be a problem in their communities.[97]

[97] Community rep KZN