"Some get healed"[1]

Research report:
Towards the development of an integrated model for the effective provision of health care at community level

October 2009

AIDS Foundation
South Africa

Developing Partnerships - Serving Communities

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
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[1] Volunteer at Nceduluntu.

Contents

List of abbreviations

AIDS	acquired immune deficiency syndrome
ART	antiretroviral treatment
AFSA	AIDS Foundation of South Africa
CBC	community based care
CBO	community based organisation
CCW	community care worker
CHBC	community home based care
CHW	community health worker
CSA	Centre for the Study of AIDS
DAAG	Douglas AIDS Action Group
DOH	Department of Health
DOT	directly observed treatment
HAART	highly active antiretroviral treatment
HBC	home based care
HIV	human immunodeficiency virus
KZN	KwaZulu-Natal
PLHA	people living with HIV/AIDS
NGO	non-government organisation
NIP	National Integrated Programme
NPO	non-profit organisation
NSP	National Strategic Plan

OI   opportunistic infection

OVC   orphans and vulnerable children

PHC   primary health care

PLHA   person living with HIV/AIDS

SETA   Skills Education Training Authority

STI   sexually transmitted infection

TB   tuberculosis

VCT   voluntary counselling and testing

WHO   World Health Organisation

Executive summary

The South African government acknowledges the need for community based care (CBC). CBC can reduce and share the costs of care within the system, evoke feelings of ownership within the community, reduce the isolation of ill people, promote a holistic approach to care, link and complement existing health services, be pro-active, and encourage the right to decide about care within the living environment.

In 2008 AFSA invested 80% of its annual income in support of community interventions by providing its partner organisations with funding, training, capacity building and technical assistance. The organisation's 62 CBO partners reached a total of 163 045 beneficiaries in the same year. AFSA is seen as a very successful 'enabling organisation', as its reliable multi-year funding stream is seen as permitting partner organisations to make project implementation their primary focus, as opposed to having to spend an inordinate amount of time on managing cash flows or dealing with funding crises.

At AFSA's behest, research was undertaken to develop new critical and conceptual frameworks for best practice models for civil society and government collaboration, so as to enable the delivery of sustained quality health care and social protection and services at community level. Research was guided by experiences and lessons learnt through the work of AFSA community partner organisations and local beneficiaries. The research process consisted of a document review, a literature review and participatory field research (key informant interviews, questionnaires, focus group discussions and observation). Findings were cross checked, and commonalities, exceptions and discrepancies noted.

A key finding was that the CBOs with the highest success rates tend to be holistic in their approaches, and to utilise an integrated model of CBC. CBOs that are effective therefore cater to as many needs as is possible in the communities they serve. Success seems to depend to a large extent on context. CBOs' efforts need to include individual, social and structural level interventions.

Benefits of AFSA involvement included being enabled to secure further funding and support, and empowerment of CBOs.

Expressed needs of CBOs included the need for more training, especially context-specific training. There is also a need for sustained government involvement, as evident in the three AFSA-supported projects in KwaZulu-Natal.

The best way for enabling organisations to support CBC is through actions such as financing, training and capacity building. Technical assistance and capacity building for CBOs is vital. Activities such as identifying and mobilising existing community resources, mobilising financial and material resources, programme management and building skills in service provision are very helpful.

CBOs need to be sensitive to, and structured around the needs of the communities they serve. Community involvement is thus vitally important, and active participation from community members should be encouraged at all times.

The field research highlighted the importance of local context. What this means is that implementing any model of 'best practice' in diverse communities, with differing relations to traditions, modernity and beliefs, is problematic. A model can be developed but implementation is context-specific, since the model needs to be able to accommodate many social, cultural, economic and historical variables.

The most effective CBOs are holistic in their approaches and, in addition to HBC, offer programmes aimed at, or partner with organisations that address, issues related to poverty alleviation, skills and capacity building. Enabling organisations and government have key roles to play.

'Best practice' is not the replication of one good system, one good project or one good funding mechanism, but rather a critical process that clearly understands and critiques 'failures' as a crucial element in developing interventions and a critical process that over time and across projects evaluates what works, taking into account the individual, social and structural contexts in which interventions take place.

1.   Introduction

> "Publicly, then, it was common cause that Jake had died because he was bewitched. Privately, the story was far more ambiguous, the line between an AIDS death and a bewitchment death much less distinct. I believe this to be true, not only for Jake's death but also for the majority' of those of young and middle-aged villagers. The more intimate one's relation is to the deceased, the less certain the cause of his or her death."[2]

Isak Niehaus argues that the association of AIDS with death is the main source of its stigma.[3] This stigma, in turn, leads to secrecy and denial on the part of those infected with HIV for fear of being socially ostracised. In purely instrumental terms, connecting AIDS symptoms with witchcraft can be seen as a way in which to externalise the blame for one's imminent death, thereby avoiding some of the related social stigmatisation.

The existence of parallel 'realities,' in which both witchcraft and a sexually transmitted viral infection simultaneously cause someone's death – depending on subject position – thus becomes perfectly rational. These parallel 'realities' help constitute a pluralisation of 'modernities' in which 'Western' and 'non-Western'[4] epistemes combine to form different hegemonic discourses.[5]

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[2] J. Steinberg. 'AIDS and AIDS treatment in a rural South African setting,' *Institute for Security Studies Monograph No. 149, August 2008.*

[3] I. Niehaus. 'Death before dying: Understanding AIDS stigma in the South African Lowveld,' *JSAS 33(4) 2007, pp. 845-60.*

[4] The terms Western and non-Western are used in quotes because they "fix the universal "other" into a conceptual space defined by negation." (J. & J. Comaroff*, Modernity and its Malcontents: Ritual and Power in Postcolonial Africa*, University of Chicago, 1993, p. xii.)

[5] U. Beck, A. Giddens & S. Lash. *Reflexive Modernities: Politics, Tradition and Aesthetics in the Modern Social Order*, Stanford, 1994, pp. 56-109; U. Beck, *World Risk Society*, Polity, 2000, p. 2-17.

As is the case with death, we conceive of sickness, disease, treatment and therapy management, community and community engagement in many different and coexisting ways. This complexity provides the backdrop to the provision of health care in South Africa. A brief review of health care provisioning follows.

Local politics, economic production and therapy are linked in complex ways. European *noso-politics* (the politics of illness) changed tremendously during the eighteenth century, for example. As the problem of the sickness of the poor began to play an important part in the relationship of the imperatives of labour to the needs of production, the health and physical well-being of populations became an essential objective of political power. This laid the foundation for what we know today as 'clinical' or 'scientific' medicine with its doctors, nurses, public health officials, hospitals and clinics.[6] In Western countries a new medical ethics, usually referred to as patient autonomy, developed on this structure. In general terms this ethical approach advocates (in theory) an end to all forms of medical paternalism.[7]

However, Western noso-politics is certainly not universal. Healing is rooted in the socio-cultural order and the management of therapy entrenched in patterns of social control over domestic and community issues. John Janzen argues that, since the 1970s, it has become apparent that "therapy managers, drawn from among the patient's relatives, neighbours, and friends" have come to stand "at the heart of African healing". In many cases therapy managers are more influential than professional medical personnel, because they hold juridical authority over diagnosis and treatment. This means that they authorise diagnosis and control treatment. But they also provide supportive care.[8] The notion of 'community based care' is therefore not a new one. But official parlance has imbued it with new meanings within the context of a substantially changed politics of illness and healing.

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[6] P. Rabinow (Ed.) *The Foucault Reader*, Pantheon, 1984, pp. 173-82.
[7] O. O'Neill. 'Public health or clinical ethics: Thinking beyond borders,' *Ethics and International Affairs 16/2 (2002).*
[8] S. Feierman & J.M. Janzen (Eds.). *The Social Basis of Health and Healing in Africa,* UC Press, 1992, pp. 1-19.

The South African Department of Health, following World Health Organisation guidelines, defines community based care (CBC) as "… care that the individual can access nearest to home, which encourages participation by the people, responds to the needs of people, encourages traditional community life and creates responsibilities."[9] Community home-based care (CHBC) forms an integral part of CBC in South Africa. [10]

According to the Gaborone Declaration on CHBC, CHBC is "[t]he care given to an individual in his/her own environment by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs."[11] A multi-country survey conducted by Mohammed and Gikonyo reported that many CBOs involved in CBC in sub-Saharan Africa felt the need to broaden the Gaborone definition by adding the following:

- providing communities with information on HIV/AIDS
- providing care to affected family members
- providing holistic care to patients, including neighbours
- using volunteers as care providers, and
- emphasising that the responsibility of CBC also lies with the ministry of health.[12]

CBC aims to make communities more responsible for, and better able to care for their own sick members. It aims to make them more self-sufficient where health care is concerned and enable them to care for the ill within the community itself, instead of relying solely on the formal health sector. It also emphasises the holistic care of PLWHA, providing for their physical, psychosocial and spiritual requirements.

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[9] B.P. Ncama. "Models of community/home-based care for people living with HIV/AIDS in Southern Africa", *Journal of the Association of Nurses in AIDS Care* 16(3), May/June 2005, p. 34.

[10] Department of Health. *National Guidelines on Home-based Care/Community-based Care*, South Africa, 2001, p. 1.

[11] N. Mohammed & J. Gikonyo. Operational Challenges: Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa, African Region Working Paper Series No. 88, August 2005, p. 2.

[12] *Ibid*, p. 7.

CBC has definite advantages in improving health care in poor, or poorly-serviced, communities. [13]

CBC models include single service home-based care, informal home-based care and integrated home community-based care. [14]

Community carers, also referred to as community care workers (CCWs) or volunteers, can fulfil a variety of functions in CBC programmes. According to guidelines issued by the South African Department of Health, CCWs can be involved in preventative care such as growth monitoring, food security and disease prevention; basic care, basic rehabilitation, hygiene and safety; support to clients; counselling; health promotion, education and therapeutic education; emergency care; referrals; and household assistance. [15] The various roles of CCWs involve aspects related to administration, care, counselling, communication, education and income generation, to name but a few.[16]

Successfully recruiting and maintaining CCWs is a challenge faced by many CBOs involved in CBC. CBC projects report a high turnover of volunteers. Once trained, many volunteers move on to other opportunities, drop out or prove unreliable. The problem is that it is unsustainable in the long run to provide a significant stipend to volunteers. Non-financial incentives are therefore necessary to motivate volunteers, such as a sense of belonging, a supportive work environment, opportunities to gain

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[13] R. M. Carelse. "The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS community based care", MA thesis, Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, April 2008, pp. 72-74.

[14] *Ibid*, pp. 75-80.

[15] Department of Health. *National Guidelines on Home-based Care/Community-Based Care*, South Africa, 2001, p. 8.

[16] *Ibid*, p. 87; T. Colton et al. *Community Home-based Care for People and Communities Affected by HIV/AIDS*, Pathfinder International, October 2006, pp. 181-193, 196-230; B. Magongo. *Community Health Workers in Gauteng: Context and Policy*, Cadre, 2004, pp. 20-21; N. Mohammed and J. Gikonyo. *Operational Challenges: Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa*, African Region Working Paper Series No. 88, August 2005, p. 8; R. Panjabi, et al. *A Community-Based Approach to HIV Care in Rural Liberia: Liberia's HIV Equity Initiative*, Ministry of Health and Social Welfare, Republic of Liberia, November 2007.

skills, and passing a thorough screening process.[17] High turnover of volunteers seems to be a significant problem in South Africa. Sometimes financial incentives are also necessary to avoid high staff turnover. The Gauteng Department of Health, for instance, implemented a policy in 2004, in terms of which volunteers were paid a minimum stipend of R500 per month. [18]

In order to ensure maximum effectiveness of CBOs engaged in CBC, CCW activities can be monitored and evaluated by using indicators developed for the purpose. [19]

CBC programmes stand to benefit greatly from sustained outside support. So-called mentoring, or enabling, organisations can consist of official government committees created to support CBC programmes, or more likely, NGOs. More often than not, outside support comes from the NGO sector. Since CBC involves the empowerment of a community to care for itself, it makes sense that enabling organisations should encourage and support the community to solve and address its own problems, rather than organisations taking up the burden on themselves. Outside help notwithstanding, resource-poor communities must carefully manage resources so as to effectively sustain CBC for extended periods of time. CBOs involved in CBC should work through existing health infrastructure and staff, and should develop an effective social network to assist in case-finding, referral and follow-up. Securing a sustainable source of nutrition for patients in the community is important, because importing food is unsustainable in the long term. Development of a local means of food production is important.[20]

As with any care programme, CBC is not perfect. Several obstacles need to be overcome to make it work more effectively. CBOs face a large number of challenges when it comes to implementing and sustaining CBC programmes. Some of the most

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[17] M. Russel & H. Schneider. Chapter 16: "Models of community-based HIV/AIDS care and support", p. 332.
[18] B. Magongo, *Community Health Workers in Gauteng: Context and Policy*, Cadre, 2004, p. 17.
[19] *Ibid*, p. 22.
[20] K. Sadler et al, "Community-based therapeutic care in HIV-affected populations", *Transactions of the Royal Society of Tropical Medicine and Hygiene* 100, 2006, p. 8.

obvious difficulties include extreme poverty, high illiteracy, lack of communication between government and CBOs, and CCW burn-out. [21] Despite these barriers, many CHW programmes in South Africa are very effective. Commonalities in these programmes include:

- multi-dimensional approaches

- good governance

- access to diverse sources of funding

- paid volunteers

- participatory methods to recruit CCWs

- standardised training and project supervision

- positive relationships between CCWs and hospital and clinic staff, and

- innovation. [22]

According to Kautzky and Tollman, South Africa was a "… global leader in the conceptualisation and development of the primary health care (PHC) approach", which included the development of the community-orientated primary care movement. For example, the Pholela Health Centre in Kwazulu-Natal in the early 1940s is regarded as one of the earliest forerunners of community-orientated care in the world. The Pholela model was apparently so effective that the relatively 'liberal-minded' government in 1944 (under General Jan Smuts as Prime Minister) thought of establishing a network of PHC centres, based on the Pholela model, across the country. [23]

The National Party took power in 1948, however, and did not implement this progressive plan. Rather, they implemented policies that were to harm the health system and the health of the majority of the population in the long term. Deregulation of health services led to the expansion of hospital-based services and

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[21] M. Russel & H. Schneider. Chapter 16: Models of community-based HIV/AIDS care and support, p. 332.
[22] I. Friedman et al. *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*, Health Systems Trust, pp. 11-21.
[23] K. Kautzky & S. M. Tollman. 'A perspective on primary health care in South Africa', pp. 17-19.

facilities and worsened the already wide disparities between urban and rural health care.

As a result of the privatisation of health care, access to quality health care was largely determined by race, income and location. In the late 1970s and the 1980s, however, CBC gradually returned to South Africa.[24]

In order to treat patients more effectively, local nurses were trained to diagnose and treat most of the common ailments found in the community, which reduced the burden on the hospitals and clinics, and opened the way to future CBC services. The Soweto uprisings in 1976 severely disrupted clinics in the townships. Politically, the Soweto uprisings brought the disparities in South Africa to increased public attention both nationally and internationally.

In the meantime, at Alma Ata, in the former USSR, 134 nations and other organisations enthusiastically embraced PHC as a means to achieve health care 'for all'. Inspired by Alma Ata and a desire to oppose the apartheid regime, a range of organisations and individuals in South Africa organised themselves into the National Progressive Primary Health Care Network (NPPHCN). The NPPHCN's aim was to encourage the implementation of PHC in South Africa. There were also several isolated attempts in the 1970s and 1980s to put CBC into practice, but many of these programs apparently failed, due to the government's inability to accommodate the principles of PHC, as well as due to a degree of government hostility.[25] According to Friedman et al., however, several generic CCW programmes flourished during the 1980s, thanks to funding provided by international donors.[26]

It was only towards the end of apartheid, in the few years prior to 1994, that PHC gained official prominence in political circles. After its election victory in 1994, the

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[24] K. Kautzky & S. M. Tollman. 'A perspective on primary health care in South Africa', pp. 20-21.
[25] *Ibid*, p. 22.
[26] I. Friedman et al, *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*, Health Systems Trust, p. 4.

ANC-headed government announced its National Health Plan, which drew much of its inspiration from PHC development in South Africa before 1948, such as the Pholela Health Centre model. It was framed by the Alma Ata Declaration and technical experts from the World Health Organisation (WHO) and UNICEF were consulted.

The National Health Plan was based on the PHC approach. Its aim was to address fragmentation and duplication of services by integrating all health services under a single ministry of health, to decentralise the organisation and management of health services, and most importantly, to make comprehensive community-based health care accessible to all sectors of society by establishing PHC centres as the foundation of the national health system.[27]

The South African government, according to the *Guidelines for Home-Based Care and Community-Based Care* (2001), acknowledges the need for CBC. CBC is not meant to become a "cheap care option" for poor communities, or to replace the formal health sector entirely, however. CBC is seen as an important strategy in implementing PHC. According to the document, CBC would fulfil the following purposes[28] in the PHC strategy: prevention, early identification and care at community level would reduce the need for costly institutional care, reduce pressure on hospital beds, reduce and share the costs of care within the system, evoke feelings of accountability and ownership within the community, allow people to spend their days in familiar surroundings and reduce isolation, promote a holistic approach to care, create awareness of health in the community, put care-givers in contact with potential beneficiaries or partners, link and complement existing health services, be pro-active rather than reactive, and encourage the right to decide about care within the living environment.

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[27] K. Kautzky & S. M. Tollman. "A perspective on primary health care in South Africa", p. 23.
[28] Department of Health. *National Guidelines on Home-based Care/Community-based Care*, South Africa, 2001, p. 5.

Good intentions notwithstanding, Kautzky and Tollman regard the government's efforts at establishing PHC (and hence more effective and comprehensive CBC) in post-apartheid South Africa as a failure. They list a variety of reasons for the failure, including administrative problems, lack of leadership and lack of commitment from politicians, a shortage of health worker personnel, deep-seated imbalances in resource distribution, the HIV/AIDS epidemic (which overburdened the health sector and demoralised it), and a curative-orientated health service. They saw the most important failure as the inability of the new government to enlist the participation of civil society in the process of implementing PHC.[29]

The opportunity to enlist the help of civil society in reconstructing the country's health system in the years after 1994 was missed because the post-apartheid government never fully harnessed the strengths of the NGO sector. As a result many NGOs and CBOs were forced to close due to a lack of funding and support.[30]

Once South Africa had a legitimately elected government, international donors switched their funding priorities, which led to the weakening of several large NGOs, and their replacement by a scattering of smaller CBO projects that had less coherence and fewer resources.[31] Another area of concern was the lack of governmental monitoring or evaluation mechanisms to ensure that CBC programmes were implemented properly, especially where orphans and vulnerable children were concerned. This made it difficult to ensure that the policies and rights concerning vulnerable parts of the population were adequately addressed through CBC.[32]

CHBC programs for PLHA were first initiated by church organisations or concerned individuals, particularly retired nurses, and the movement expanded. Some of these organisations, however, reported that accessing financial and human resources,

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[29] K. Kautzky & S. M. Tollman. "A perspective on primary health care in South Africa", pp.23-25.
[30] Ibid, pp. 24, 27-28.
[31] I. Friedman et al. Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes, Health Systems Trust, p. 4.
[32] T. Mamaila. Community-based care for HIV/AIDS orphans. MA thesis in Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, May 2005, pp. 36-40.

especially government resources, was exceedingly difficult. This was exacerbated by the different reactions of different provinces in implementing and supporting CBC initiatives.

Ncama mentions that the government appeared to be taking CBC more seriously in 2000, when it organised a joint health and social development meeting, where the provinces were presented with different models of CBC and encouraged to implement and modify them to suit their situation.[33] In Gauteng, the response to CBC was relatively positive. The Gauteng HIV/AIDS directorate, in 2000 at least, had a full-time staff member dedicated to liaising with CBC organisations. From 1999 to 2001, the number of government-backed NGOs in Gauteng which organised CBC increased from 17 to 57. In the other provinces, however, CBC fared much worse.

For its part, the South African government expects civil society to fulfil functions similar to what civil society is demanding from government: identifying community needs and priorities, including financial needs; conducting outreach to members of communities; conducting operational co-ordination, facilitating planning and collaboration; monitoring and evaluating service patterns, quality of care and consumer satisfaction; optimisation and control of available resources; advocating and lobbying for services and resources, as well as advising the formal system; negotiating with other sectors; developing sustainable care programmes; administering direct care: preventative, curative, therapeutic, rehabilitative and palliative; capacity building and supporting caregivers; leadership; identifying consumers and service providers; dealing with suspected abuse; conducting disciplinary measures and complaints; and referrals.[34]

Lucy Gilson has stated in no uncertain terms that there is a crisis of trust in the South African health-care system. This goes for patients, doctors, nurses, wage negotiators

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[33] B. P. Ncama. "Models of community/home-based care for people living with HIV/AIDS in Southern Africa", *Journal of the Association of Nurses in AIDS Care* 16(3), May/June 2005, pp. 38-39.
[34] Department of Health. *National Guideline on Home-based Care/Community-based Care*, South Africa, 2001, pp. 6-8.

and commentators.[35] Aligning the expectations of the Department of Health and community based health workers (CBHWs) will go a long way towards addressing the crisis. Whilst it is true that CBHWs and the CBOs they work for are integral to the functioning of the healthcare system, the work of volunteers who earn stipends should not let government off the hook as far as its responsibilities to ensure health and wellbeing are concerned. Working with and alongside therapy managers, CBHWs are in a position to strengthen the comprehensive home-based response to HIV and AIDS, TB and PHC. This will only be possible, however, if a number of issues are successfully addressed. These include accountability, policy, leadership, remuneration, recruitment, support, training and evidence-based education.[36] It is also crucial that CBOs are well funded, both by government and through their own active and aggressive marketing, in order for them to be able to provide community members and CBHWs with the necessary support and care and to ensure sustainability. Government has committed to addressing these issues. The HIV & AIDS and STI National Strategic Plan 2007-2011 seeks to "strengthen and improve the efficiency of existing services and infrastructure and introduce additional interventions" and "be relevant to all agencies working on HIV and AIDS in South Africa, within and outside government." In order to strengthen human resources for health, the plan stresses "defining clear responsibilities for the use of … community care givers."[37]

The purpose of this research is to provide a focus to guide government and civil society interaction with CBOs so as to optimise the positive contributions to 'modernities' by the people respective CBOs serve, by ensuring the delivery of sustained quality health care and social protection services.

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[35] L. Gilson. "Trust and the development of health care as a social institution," *Social Science and Medicine* 56(2003) pp. 1453-68; L. Gilson. "Trust and health worker performance: exploring a conceptual framework using South African evidence," *Social Science and Medicine* 61(2005) pp. 1418-29; L. Gilson. "Trust in health care: theoretical perspectives and research needs," *Journal of Health Organization and Management* 20/5(2006) pp. 359-76.
[36] I. Friedman et al. *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes,* Health Systems Trust, 2007.
[37] SANAC. HIV & AIDS and STI National Strategic Plan, 2007-2011.

2.   Background

a. The brief

Research was undertaken to develop new critical and conceptual frameworks for best practice models for civil society and government collaboration, so as to enable the delivery of sustained quality health care and social protection services at community level. Research was guided by experiences and lessons learnt through the work of AFSA community partner organisations and local beneficiaries, as stipulated in the terms of reference.

The research sought answers to the following questions:

- How does the state deliver quality care in the face of a crumbling and overburdened health system, high levels of infection, increasing poverty, malnutrition and social cynicism, despite the ideals outlined in the National Strategic Plan (NSP)? What policies should government think of adopting, what programmes should be developed, and what new models can be defined and refined to change the way the official version of health, as well as the lay version of health, are framed and shaped?

- How do communities perceive the provision of health care services and the role of the state and community based programmes?

- How is it possible to deliver high-quality health care and services through the use of volunteers and non-permanent staff?

b. The organisation (AFSA)

In 2008 AFSA invested 80% of its annual income in support of community interventions[38] by providing its partner organisations with funding, training, capacity building and technical assistance. The organisation's 62 CBO partners reached a total of 163 045 beneficiaries in the same year.[39]

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[38] "Filling the gaps in the National Integrated Plan: internal evaluation and documentation of AFSA and government collaboration in implementing the NIP programme in 10 drop-in centres in KZN and Limpopo provinces of South Africa", AFSA, May 2008.

[39] AFSA annual report to Atlantic Philanthropies, January to December 2008.

AFSA is seen as a very successful 'enabling organisation'. Its reliable multi-year funding stream is seen as permitting partner organisations to make project implementation their primary focus, as opposed to having to spend an inordinate amount of time on managing cash flows or dealing with funding crises. This means that the momentum of CBO project implementation is not disrupted or lost due to delays in the receipt of funding. Moreover, the flexibility of AFSA funding allows CBOs to adjust their budgets when circumstances change.[40] AFSA's funding is unique in that it is both reliable and flexible. This facilitates planning and the ability to credibly pursue additional sources of funding, thus helping to ensure sustainability.

Many of AFSA's partner organisations were chosen because they had a strong focus on HBC, because AFSA identified HBC as an area in which service delivery was not optimised due to a lack of capacity at the tipping point.[41] However, HBC does not occur in a vacuum. Therefore AFSA encourages its partner organisations to engage addressing in other social and health-related issues so as to strengthen the communities they serve. It is clear that AFSA has a commitment to seeing that community-based projects succeed and that these are sustainable in the long term.

To address gaps between government policy and service delivery, and to limit "new HIV infections and mitigate the impact of HIV and AIDS in vulnerable communities, and effect policy, cultural and social change in South Africa", AFSA provides a package of support and services to its CBO and NGO partners, over a multiple-year period. This entails:

- "Equipping NGOs & CBOs with essential financial resources to implement relevant and effective HIV & AIDS interventions in their constituencies

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[40] Email correspondence with Debbie Mathew, 7 October 2009.
[41] Interview conducted with AFSA Executive Director, Debbie Mathew, Durban, July 2009.

- Developing the skill sets of CBO community care workers (CCWs) and personnel to enable them to render appropriate and quality services and interventions with target populations, and

- Building the organisational capacity of NGO and CBO partners for the purpose of good governance and effective planning, monitoring and evaluation, thereby equipping them to demonstrate impact and enhancing their prospects for long-term sustainability."[42]

c. Methodology and instruments

The research process consisted of a document review, desk research (a literature review), and participatory field research (key informant interviews, questionnaires, focus group discussions and observation). Findings were cross checked, commonalities drawn on, and exceptions and discrepancies noted.

The literature review explored a range of issues to inform the content of the research tools and provide a context for the analysis of the data and suggestions for the way forward. It examined, among other topics:

- Community-based care in South Africa, with emphasis on the relationship between the state and civil society

- Legal and ethical frameworks for community care

- The role of mentoring/enabling organisations in supporting CBOs

- The role of community carers in health and social protection at local level

- Whether the role of community carers should be broadened to include other aspects

- Sustainability of community based programmes, and

- Promising practices in African settings.

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[42] AIDS Foundation of South Africa (AFSA). "Strengthening civil society for effective intervention in the HIV and AIDS epidemic, Request for funding from the Atlantic Philanthropies, 30 September 2009.

Field research was participatory and qualitative in nature. Interviews were conducted at sites identified by AFSA. During key informant interviews, the following categories of key informants were interviewed:

- The AFSA Executive Director, Deputy Director and Programmes Manager
- Relevant AFSA Project Officers
- AFSA Capacity Building Officers
- A sample of CBOs Managers (or coordinators managing programmes)
- A sample of CCWs engaged in community care programmes
- A sample of community beneficiaries
- Relevant government officials, and
- Relevant people snowballed from the above categories.

The topics for key informant interviews were developed in line with the themes outlined in the literature review. Questionnaires, based on the same themes, were developed for select participants, and focus group discussions held with a range of stakeholders. In each site a discussion was held with:

- Community health workers
- Community beneficiaries, and
- Staff members of CBOs.

d. The research team

Menzi Hlongwa is a Project Officer at the Centre for the Study of AIDS, University of Pretoria. He holds a BCom Law degree from UKZN.

Sean Lotriet holds a BA from the University of the Witwatersrand and a BA (Hons) in Psychology from UNISA. Sean does consultancy work and is a shareholder in Sinethemba Consulting.

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3. Sites visited and brief descriptions

a. Eastern Cape

Mahlungula Foundation is located in the Isikelo Location, Bizana District. The foundation's primary area of focus is home-based care. Other services rendered at community level include VCT, counselling, health education,[43] poverty alleviation, skills development, awareness campaigns and vegetable gardens. The foundation's staff complement consists of four full-time staff members, and twelve stipended volunteers.

Nceduluntu Home Based Care is located in the Chithwa Village near the town of Mount Ayliff. Services rendered to local communities include home-based care, food gardens, an OVC project, a drop-in centre and health education. The project has 6

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[43] Interview conducted with Cecilia Nqambi, Bizana.

full-time staff members working in programme implementation and office management, and 29 volunteers, 20 of whom receive stipends.

b.   KwaZulu-Natal

Bhekuzulu Self Sufficient Project is located in the Bhekuzulu area just outside the town of Estcourt in northern KwaZulu-Natal. Started in 2004, it provides services to the people of the Imbabazane Municipality in the Uthukela District. Services include prevention and awareness programmes, advocacy and lobbying for PLHA, home-based care, an OVC programme, food gardens, a feeding scheme, a halfway house and income generation.[44] The staff complement consists of 9 full-time members involved in programme implementation and office administration, 30 volunteers – 20 of whom receive stipends – involved in HBC, and one international volunteer.

KwaHilda Ongcwele Community Care Centre, outside the town of Newcastle, services the Osizwene Township in the Amajuba District. The centre was founded in 2002, received NPO status as an HIV/AIDS Centre in 2003, and became a community care centre in 2005. It offers integrated services that include an OVC programme, a home-based care programme, a community awareness project, and poverty alleviation programmes such as a soup kitchen and vegetable gardens.[45] Staff is made up of 14 full-time members, 32 stipended, 29 non-stipended and 1 international volunteer.

Nqutu AIDS Action Group is located outside of Dundee in northern KwaZulu-Natal. Services provided to local communities include home-based care, skills development programmes, a VCT programme, food gardens, food parcels, an OVC project and an HIV/AIDS awareness programme.[46] The group is staffed by 24 full-time members, 50 stipended community workers, and 1 international volunteer.

c.   Limpopo

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[44] As One Newsletter, 1(1) April 2009.
[45] KwaHilda Community Care Centre Newsletter 1(1) July 2009.
[46] Interview conducted with Jabu Buthelezi, Nqutu AIDS Action Group.

Fanang Diatla Self Help Centre is located in the Gamathabatha Village (Legwareng), Capricorn District. Services rendered to the local community include income generation projects, stokvels, burial societies, a bakery, a village bank, feeding schemes, home-based care, food gardens and poverty alleviation initiatives. Ten fulltime staff members and 58 volunteers work at the centre.

d. Mpumalanga

Masoyi Home Based Care is situated between the towns of White River and Hazyview, and services the Masoyi tribal region. It provides home-based and orphan care, food gardens, community multi-care centres, youth programmes, a scholarship programme, a programme for young mothers and a child-headed household programme. Local volunteers and community members are actively involved in each of the components.[47] Thirty two full-time staff members and 98 volunteers – 65 of whom receive stipends – work at Masoyi.

e. Northern Cape

Douglas AIDS Action Group is located in the Bongani Township outside the town of Douglas. Services rendered to local communities include education for prevention, rehabilitation of prisoners, home-based care, and VCT and OVC programmes. Five fulltime staff members and 10 stipended volunteers make up the staff complement.

Tshepo ya Sechaba opened its doors in 2000. It is located in De Beershoogte, just outside of the town of Barkly West. Services rendered to local communities include an OVC programme, home-based care, HIV/AIDS awareness training, counselling and food gardens. The organisation is staffed by 2 full-time staff members and 21 volunteers receiving stipends.

4. Findings presented thematically according to TOR

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[47] Masoyi Home-Based Care promotional flyer.

a. CBO efficacy in addressing health and social aspects of HIV, TB and OVC

An informant at the Mahlungulu Foundation remarked that the number of AIDS-related deaths in the area had markedly decreased since the introduction of HBC. A volunteer at Nceduluntu, on being asked what happened to most people who receive home-based care, responded similarly that "some get healed". These sentiments were echoed in the Northern Cape and at several sites in KwaZulu-Natal. This shared belief seems to be based on empirically measurable evidence, with organisations recording how many bedridden clients recover and go on to lead full and productive lives. However, the picture is not uniformly encouraging. At KwaHilda, for instance, "the number of chronically or terminally ill clients who are bedridden and in need of home-based care grows and the DOH is unable to supply us with enough of the badly needed care kits."[48]

At Mahlungulu Foundation an informant noted that awareness campaigns and VCT had resulted in positive sexual behaviour change. However, it should be noted that there is a vast literature on problems related to self-reported behaviour change. Also, demand for condoms does not necessarily reflect use. In KwaZulu-Natal too, many informants expressed the belief that awareness campaigns had affected positive sexual behaviour change (although evidence of low levels of condom usage in some places contradicts this). Sexual behaviour change is notoriously difficult to measure, however, so these remarks should be read as anecdotal.

At Tshepo ya Setshaba caregivers reported that their work had led to a reduction in social stigmatisation in local communities: "*Pasiënte is nie bang nie, hulle kom na ons toe* [Patients are not afraid, they come to us]".

Yet much still needs to be done. While all CBOs visited mentioned challenges and problems these were generalised, as discussed in these findings, rather than specific. At Masoyi Home Based Care an informant noted that she would "be very happy if"

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[48] KwaHilda Community Care Centre Newsletter, 1(1) July 2009.

they could "decrease the number of TB-related deaths" and hence also "the number of orphans". To this end she wanted but is yet to start a directly observable treatment (DOT) programme.

In the Amajuba District of KwaZulu-Natal – a region serviced by KwaHilda Ongcwele Community Care Centre – it was recently estimated that 55% of the area's 160 000 children under the age of 15 years live in poverty, and that a further 15% are orphans. Moreover, the number of OVC in the area is increasing and promises to increase even further still in the face of the HIV and AIDS epidemic, poverty and unemployment. Given that KZN Health Department funding of KwaHilda's OVC project had recently been cut by 35%; that AFSA funding, constituting a third of the project's total funding, comes to an end in 2009; and that other funders such as First Rand, First National Bank, De Beers, Anglo American and Momentum are tightening their belts, KwaHilda faces an uphill battle.[49] Even at BhekuZulu Self Sufficient Project, where a total of 300 children receive care and support,[50] the frequency of meat rations had to be reduced due to cutbacks in funding from the KZN Health Department.

Many people still live in abject poverty, making them more susceptible to the impact of HIV and AIDS. It is therefore worth mentioning that the CBOs with the highest success rates tend to be holistic in their approaches. CBOs that are effective therefore cater to as many needs as is possible in the communities they serve. This point is elaborated in Section 4 C.

b. Employing CCWs and training

AFSA has a nuanced view with regards to the optimal ways of empowering and managing CCWs. According to the most recent draft of the Departments of Health and Social Development's Community Care Worker Management Policy

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[49] KwaHilda Community Care Centre Newsletter, 1(1) July 2009.
[50] As One: BhekuZulu Self Sufficient Project Quarterly Newsletter, 1(1) February-April 2009.

Framework,[51] which can be seen as indicative of policy direction, NPOs will be supported to employ CCWs, rather than government employing them directly.

Certain organisations are calling for CCWs to be formally employed by the Departments of Health and Social Development.[52] This is partly due to concerns about a tendency towards 'labour broking' and lack of 'decent work', which AFSA shares. While direct government employment is seen to have led to problems of appropriate deployment, lack of supervision, quality control, accountability and support, it is AFSA's view that CCWs who are based at health facilities, such as clinics, should indeed be directly employed, supervised and supported by government departments.

On the other hand, CCWs who are engaged in community outreach work, such as home-based care, health promotion and support for vulnerable households and OVCs, should be employed by local NPOs. Accordingly, CCWs should be recruited, trained, deployed, managed and supported by NPOs. These costs should be financed by means of government grants to those NPOs. CBOs that face capacity constraints could partner with larger NGOs to help manage the payroll.

AFSA's reasoning is three fold. Firstly, experience and research have shown that NPOs cannot effectively supervise and monitor CCWs who are not employed by them, because the CCWs do not recognize the authority of the NPO to manage them. Secondly, government does not have the capacity effectively to monitor and support CCWs in the field. Thirdly, if government were to employ CCWs directly, it would not be able to afford to fund NPOs to provide the necessary support and supervision. As a result, many small CBOs would close, thus reducing the level of community participation in local health care delivery.

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[51] Departments of Health and Social Development. *Community Care Worker Management Policy Framework, Draft Version 6.0,* 2009.
[52] ALP. Open letter to Ministers of Health, Economic Development, Social Development, and Labour, dated 29 June 2009.

AFSA also holds very particular views on what constitutes appropriate training for volunteers. It believes that the training and qualification requirements for CCWs should not exclude people who have limited literacy but significant experience and dedication. The new policy framework (Version 6.0) minimum requirements are designed to be inclusive. Volunteers who have a commitment to care work but not much formal education should therefore be able to enter the training programme for Ancillary Health Care NQF Level 1 (ABET Level 3). It has been proposed in various quarters that in order to be eligible for a government-funded stipend or salary under the proposed new system, people should have successfully completed training to NQF Level 3. Of course, AFSA supports the establishment of professional standards and career-pathing. However, it is concerned that those who do not reach NQF Level 3 should not be disqualified from receiving a government-funded stipend. Otherwise, significant numbers of mature and dedicated CCWs would be excluded from the programme.

AFSA has found that mature and experienced caregivers with an Ancillary Health Care (NQF Level 1) qualification have proven to be highly skilled and effective. According to the Institute of Development Studies' Information Team, "CHWs with minimal additional training can deliver treatment for important diseases, such as malaria, HIV and tuberculosis (TB)."[53]

However, these sentiments are not echoed by most participants in this research.[54] Moreover, a report published by the Health Systems Trust highlights the importance of high-quality training, stating that the "principal benefit to the CHW is the training received".[55] A lot of thought needs to go into appropriate levels of training for CCWs.

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[53] Institute of Development Studies, Eldis & DFID. *Providing High Quality Accessible Information to Policy Makers and Practitioners Working in Health and Development*, 27 February 2008.
[54] See section 4 C.
[55] D. Cruse. *Community Health Workers in South Africa: Information for Provincial Policymakers*, Health Systems Trust, October 1997.

This much is evident if we consider that "standardising CHW training in the USA took 10 years to accomplish."[56]

c. Success stories and lessons learnt

Some initiatives aimed at poverty alleviation seem to work remarkably well in response to a range of issues. At Fanang Diatla, for example, a widowed community member with 6 children reported that she was able to support her family by making and selling sofas. She had acquired the necessary skills by attending a course organised by the organisation. What is more, Fanang Diatla has established and is operating a successful community bank that employs community members and lends money at interest rates that offers people a viable alternative to the exorbitant commission charged by cash loan businesses. Similarly, the organisation has started a co-op bakery that supplies bread to the community and employs 18 community members.

Staff and volunteers from Masoyi Home Based Care actively engage in identifying people in the local community who live in poor housing conditions, repairing their homes where this is feasible, or else building them new homes. This research team observed two such cases. In the first a woman and her two young children, one an infant, had spent the whole winter in a camper-tent. When the team from Masoyi started building the family a new home the mother was presenting symptoms consistent with full-blown WHO stage four AIDS. The woman was put on a treatment regimen, the family put on food aid, and a new house built. The research was conducted when the building was nearing completion. The difference to the family's life was not only visible, but astonishing.

In the second case, two orphaned teenage boys who had been left to their own devices built themselves n a makeshift house composed of tarpaulin, plastic and bits of wood. It was neither wind nor water resistant and it could not be locked. The

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[56] M. Clarke, J. Dick & S. Lewin. 'Community health workers in South Africa: Where in this maze do we find ourselves?', *SAMJ* 98(9), 2008.

elder of the boys had joined a gang and the younger was considering dropping out of school. Their new home – a brick building with two rooms – had made such an impact on their lives that they managed, through Masoyi, to win scholarships that would see them through secondary school.

Where CBOs are successful there is usually a 'champion' at the helm, steering the ship. This raises issues about sustainability. When asked whether their project would continue to be successful if the director were to leave, most respondents at the more successful CBOs tended to answer in the negative. The main reason seems to be that 'champions' are not merely excellent managers, but that they also have very good networking skills and are thus well positioned to market their respective organisations. Where AFSA is the primary source of funding, the majority of managers tend to not have developed such good networking and marketing skills. It is also often the case that the 'champions' work even when there is no income, so it is not just the loss of skills that undermines sustainability but the loss of unfunded time. Organisational development therefore needs to include succession planning.

A clear division between boards and managements seem to be indicative of successful projects. This was not the case at the Douglas AIDS Action Group (DAAG), where the local mayor served on both the management and board of trustees of the organisation (as treasurer). Although no causal relationship is implied, it bears mentioning that the organisation recently had its funding suspended due to possible financial irregularities.

d. Benefits arising from AFSA involvement

The more successful CBOs visited, such as Fanang Diatla, Masoyi and Bhekuzulu, were able to use AFSA funding as a springboard. They have all been able to secure additional donors and to start projects that have gone a long way towards making them self-sufficient and sustainable. Fanang Diatla, for example, secured funding through Anglo Platinum with which to build a bakery that functions as a co-op and employs 18 people from the community (15 women and 3 men), and in addition supplies the community with subsidised bread. Bhekuzulu, too, has secured funding

for and subsequently built an on-site bakery. It is possible that the manner in which AFSA funds and its flexibility laid the foundation for its partner organisations to secure further funding and support.

At many of the organisations visited, community health workers benefited greatly from AFSA involvement. At Bhekuzulu an informant reported that she had started at the organisation as an unpaid volunteer and that she is now a social auxiliary worker, due in large part to AFSA training. At Fanang Diatla, a volunteer reported that she is now in a position to support her three children as a single mother and primary breadwinner, due in large part to training provided by AFSA. Apart from supporting CBOs in the delivery of much needed services with regards to HBC, AFSA involvement clearly empowers community members in a host of different ways.

It bears mentioning, however, that CCWs in Limpopo, the Northern and the Eastern Cape expressed the need for more and/or higher levels of training. At the Douglas AIDS Action Group, for instance, volunteers reported that they would prefer accredited training to an increase in their stipends (which amounted to only R500 per month, which the majority thought insufficient to get them through the month). CHWs at Fanang Diatla reported a need for management courses so as to be able to make better decisions when helping patients/clients. Their counterparts at the Mahlungulu Foundation, too, expressed the need for more training. When this research was undertaken, one of the more successful CBOs, namely BhekuZulu, had recently been certified as a training institution.

As was to be expected, it is community members that benefit most from AFSA involvement. In July 2009 KwaHilda Centre reported feeding and providing after school enrichment programmes to 120 OVC, providing ARV compliance monitoring to 300 people, and home-based care to in excess of 1 000 people per month, and – by way of food parcels and assistance with "door-sized food gardens" – impacting on

the food security of over 1 000 people per month.[57] The majority of CBOs visited reported similar outcomes.

The question that needs to be posed is: why do some CBOs do well and others less so? CBOs are recognised and acknowledged as 'best practice' when they are functioning well or at the best level of service delivery. However, as the cases of KwaHilda and BhekuZulu show, even acknowledged excellence[58] can be faced with problems of sustainability in unpredictable government and donor funding.

While secure start-up or continuation funding is essential, success depends to a large extent on context. It is essential that CBOs' efforts include individual, social and structural level interventions. Examples of individual-level interventions could include interventions such as VCT and patient preparedness for ART; educational interventions such as peer-to-peer individual sessions; group training sessions; psychological interventions like individual, partner and family counselling; awareness-raising; and proven methods of behaviour change.

Social-level interventions may include stigma mitigation; attempts at shifting community norms through mobilisation and coalition building; building positive social capital and social cohesion by enhancing networks and supportive links; working with sexual networks; and working in educational institutions, faith communities and other institutions of influence.

Structural-level interventions target conditions outside the control of single individuals. At an intermediate level this might include: setting up local testing and treatment centres, and offering social services such as grants. At macro-level structural interventions target conditions that shape the nature of a society.

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[57] KwaHilda Community Care Centre Newsletter, 1(1) July 2009.
[58] KwaHilda and BhekuZulu have been listed among the top 10 community care centres identified by the government's National Integrated Plan.

Examples could include poverty alleviation programmes and addressing gender inequity.[59]

e. Possible further government involvement

Most provincial departments suffer from poorly staffed services. Creating innovative partnerships with CBOs would increase their staffing and reach capacity, as well as give them feedback on the needs of the community. Provincial departments need to consider formal, fixed time memoranda of understanding with accredited CBOs.

Evidence suggests that there is much need for greater and more sustained government involvement. At the most basic level, CBOs need financial and material assistance. KwaHilda Community Care Centre, for instance, reported that it was "forced to exit children from the feeding scheme due to reduction in the funding from the Department of Health."[60]

Caregivers in Tabankulu reported that they "really need [surgical] gloves," "medicine and medical dispensers," "food parcels because people need to eat before they take their medication" and "transport because the ambulance doesn't come when we need assistance." A volunteer at the same CBO suggested a need for "more money for food and the [vegetable] garden" and "[warm] clothes for us and the children." Yet another expressed a need for piped water and a tractor for the food garden "because we plant with our hands."

An informant at Nqutu AIDS Action Group noted that it would be much easier to "give skills to the community and volunteers" and to retain employees if the Health Department were to fund the organisation's volunteers, because of the high turnover rate. Similarly, an informant in Bizana reported that "we need more health workers … and we need social workers, because we don't have a social worker." We "find vulnerable children and we don't know how to deal with them, so when there

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[59] P.W. Brouard, *UFS keynote address*, Bloemfontein, 19 October 2009.
[60] KwaHilda Community Care Centre Newsletter, 1(1) July 2009.

is a social worker it will be easier to deal with that case." At Masoyi an informant reported that many nurses start home-based care programmes but that "the problem is that the government will only fund it for a year so if [whoever runs it] lack skills it only run for that year or a year and a half and dissolve." Seeing that the majority of local nurses are not trained in marketing, more sustained government funding might very well help these projects to be more sustainable.

In one respect provincial health departments might do well if they were to replicate the example of KwaZulu-Natal. KZN DoH and AFSA had facilitated the establishment of links between all three organisations visited in the province and an international volunteer organisation (in this case the United States Peace Corps). These links proved to be invaluable in all three cases as the international volunteers that came to be involved at these organisations brought along with them an array of technical expertise and networking skills. The result was that these three CBOs all had their own website, or were in the process of getting one. Every CBO visited in KZN had established, or was in the process of establishing, working relationships with donor organisations outside of its immediate sphere of influence, due in no small part to the marketing done by international volunteers.

This is not to suggest that all Health Departments should pressure the CBOs they deal with to take on Peace Corps volunteers, but rather that they come up with and implement resourceful ways of getting technical know-how and networking skills to the grassroots level where it is so desperately needed. This is especially true for the Eastern Cape CBOs visited, because of their location in poorly resourced, underdeveloped areas formerly known as 'homelands'. In Tabankulu elderly home-based caregivers noted that they had to teach themselves how to operate the computer that had been donated to their organisation. This was a long and arduous process, and young community members accused them of being 'amaqaba' – literally meaning 'red' or 'ochre' people, denoting backwardness – and demanded that they be replaced by younger, more sophisticated, computer-literate people (such as themselves, of course). These elderly 'gogos' are excellent caregivers, and were almost ousted because of a lack of technical expertise. It is also worth

mentioning that the CBOs in Tabankulu and Bizana, located as they are in resource-deprived settings, are almost entirely (if not completely) dependant on AFSA funding.

Whilst government departments such as Social Development, Education, Health and Agriculture are heavily involved in capacity building through training, a lot more can still be done. Firstly, care should be taken to ensure that training is context specific. In Tabankulu, for example, where the Department of Social Development trains volunteers in counselling and provides annual refresher courses, one volunteer reported "we have a problem with some of the training methods because they don't know our problems." Another noted a "need [for] basic education on HIV for the kids and the community."

In KwaZulu-Natal an informant explained low levels of condom usage in the community in the following terms: "They do not want to use condoms because they think that the condom itself has AIDS, and if you put hot water in the condom, there will be worms." This highlights the point made in the introduction that in HIV and AIDS we are often dealing with competing explanations and parallel meanings.

Training on the needs of, and how to empower, different marginalised groups also seem necessary. At Masoyi, for instance, when asked whether the centre has staff members who deal with issues relating to sexual orientation, a member of a discussion group answered, "We do not have. But we have four albinos."

CBOs that operate in resource-limited settings usually rely solely, or primarily, on AFSA and government funding. Many of these CBOs, such as the Douglas AIDS Action Group and Tshepo ya Setchaba, report competition between themselves and other CBOs involved in home-based care. Some even reported conflict between their home-based carers and nurses from local clinics, who feel that they are "stealing their work." Some kind of mediation aimed at establishing better working relationships between these groups will go a long way towards strengthening the communities in which they operate.

It has already been noted that problems with service delivery due to lack of capacity at the tipping point has led to AFSA's focus on HBC.[61] It is perhaps also worth mentioning that while government policy recognises and supports the important role of civil society, national and provincial AIDS programmes are frequently ill-equipped to provide financial and technical support to CBOs. Challenges faced by the CBOs visited include high levels of bureaucracy, delays in the approval and disbursement of funds, lack of short-term funding, and capacity-building activities frequently being ad hoc, whilst not being followed up with mentoring and work-place support. Civil society organisations encounter similar problems with parastatal donor agencies, and stringent criteria and complex application procedures oftentimes preclude smaller CBOs from accessing funding.

5. Discussion of findings in light of a review of the literature

The findings of this report correlate in many important respects with the extant literature summarised below.

The majority of CBOs visited were successful (albeit to differing degrees) in enabling communities to look after their sick members, to empower people to cope with the needs of PLHA, to educate about prevention, to support family members as caregivers, and to reduce the impact of HIV and AIDS on those infected and affected. Evidence also suggests that many of the same advantages reported in the literature (see section 5.1 (b), below) resulted from CBO involvement in CBC.

Furthermore, evidence seems to suggest that integrated and holistic models of CBC are most likely to show positive results. This is also consistent with the literature. CCWs at the sites visited fulfil roles comparable to those cited in the literature (see 5.1. (d), below). A relatively common challenge is that CBOs find it difficult to train and keep CCWs on staff. This is because they frequently and steadily get 'poached'

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[61] See pp. 17-18.

by government departments, clinics or other NGOs that offer better paid jobs. This threatens sustainability and potential sustainability, and affects some organisations more than others.

Our evidence agrees with the literature that volunteers are key to effective service delivery. Finding ways in which to increase volunteers' stipends and hence to keep them at CBOs for longer periods of time therefore seems crucial if sustainability is to be achieved. Increased and more regular funding from government and civil society should be negotiated.

In terms of challenges and lessons learnt, a comparison of evidence and the extant literature suggests that the CBOs visited and similar organisations in South Africa and Southern Africa face many of the same obstacles (see 5.2 below).

The literature and evidence also agrees that outside support from 'enabling organisations,' especially with regards to financing, training and capacity building, can greatly benefit CBOs (see 5.3 below). In terms of increased CBO capacity to plan, implement, and monitor and evaluate care programmes, AFSA involvement has lead to the following successes:

- There was a 62% increase in the number of community care workers benefitting from skills building from 1 January 2006 to 31 December 2008
- 536 learners underwent accredited and/or unit standard aligned training between 01 June 2006 and 30 June 2009
- 86% of CBOs were fully compliant in terms of performance and accountability between 1 January 2006 and 20 June 2009, and
- During 2008, AFSA's 62 CBO partners engaged in community care projects that rendered services and reached 163 045 beneficiaries.

In terms of service provision at community level the following successes were reported:

- In 2008, 74% of AFSA's CBO partner organisations secured funding from government departments to support community care programmes, and

- Collectively, AFSA's 62 partner CBOs utilised the services of 1 816 CCWs. The wages or stipends of 1 305 CCWS were financed in full or partially by funds that originated from government departments.

The extant literature and evidence indicate that although government is heavily involved in the work of and support CBOS in a variety of ways, the need for even more involvement is great (see 5.4 below).

5.1.   CBO efficacy in addressing health, HIV, TB and OVCs
a. Objectives of CBC

Carelse (2008) and the Department of Health (2001) list a number of objectives of CBC programmes[62], which include the following:

- To provide structures, resources and a framework that enables a family or a community to look after its own sick members

- To empower a family or community to cope effectively with the physical, psychosocial and spiritual needs of people living with HIV/AIDS (PLWHA).[63]

- To educate a community about HIV prevention

- To support families in their role as caregivers, and

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[62] R. M. Carelse. The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS community based care, MA Thesis, Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, April 2008, p. 71; Department of Health. *National Guidelines on Home-based Care/Community-based Care*, South Africa, 2001, pp. 8-9.

[63] Mamaila (2005) has a useful definition of empowerment: *"Empowerment entails the process by which communities that are considered "powerless" are encouraged to become aware of the power dynamics affecting their lives [such as gender power imbalances and poverty]; develop skills and capacity to gain more control over their lives; exercise this control without infringing on the rights of others; and support the empowerment of others in the community."* T. Mamaila. *Community-based Care for HIV/AIDS Orphans*, MA thesis in Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, May 2005, p. 61.

- To reduce the social and personal impact of HIV on PLHA and those affected by it.

It is important for CBCs to establish effective referral systems. A referral system refers to a strong network of trusted caregivers who are able to refer community members in need of serious medical attention or help to the appropriate service provider. In return, these service providers ought to communicate to their patients/clients through the network of caregivers/CCWs.

b. Advantages of CBC

Carelse (2008), O'Connel et al. (2008) and the Department of Health (2001) mention the following advantages of CBC:[64]

- People who are very sick or dying may prefer to stay at home in familiar surroundings. Home care helps reduce the feeling of loneliness or isolation that some people may experience in hospitals. Elderly people may also prefer home-based care, since many become confused or debilitated in hospital.

- CBC is less expensive for families, since it saves on transportation costs. It also enables family members to care for an ill person and continue working.

- It eases the pressure on doctors, nurses and other health professionals, since it enables them to treat those patients who are critically ill more effectively. For example, CCWs and caregivers in home-based care models are able to effectively treat typical conditions such as cellulites, deep vein thrombosis and community-acquired pneumonia that normally require a hospital stay of two days.

- It reduces the strain on provincial and national health care budgets, especially in those areas where money is limited.[65]

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[64] R. M. Carelse. The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS community based care, MA Thesis, Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, April 2008, pp. 72-74; Department of Health. *National Guidelines on Home-based Care/Community-based Care*, South Africa, 2001, pp. 9-10; T. J. O'Connel et al. "Clinical process redesign for unplanned arrivals in hospitals", *MJA* 188, 2008, p. S19

- It helps to increase HIV/AIDS awareness and breaks down fear, ignorance and discrimination in the community. A program in Zambia reports that the mere presence of caregivers and CCWs seen caring for PLHAs helped to reduce stigma.[66]

- Culturally, it is friendlier.

- CCWs can play a crucial role in monitoring and supporting ART adherence. A famous example of such a strategy is directly observed treatment for HAART.

c. Models/approaches

Carelse's MA thesis (2008) identifies three broad models of CBC/CHBC:[67]

- The *integrated home community based care* model aims to link all service providers in the community with patients and families. Patients and families are supported by a network of services that can include CCWs, clinics, hospitals, support groups and NGOs. The model emphasises a 'continuum of care' to ensure adequate coverage and sustainability. For this model to work, an effective system of referral is necessary, which entails a great deal of trust in the community. Community caregivers need to be trained, supported and supervised. For example, HASA's integrated model aims to link four partners involved in/with HIV/AIDS: PLWHA and their families, CCWs and hospices, clinics and hospitals. In theory this system provides a continuum of holistic, quality care from when a patient is diagnosed with HIV to the patient's death. CCWs work in teams of two supervised by a registered nurse, and undergo three months training in theory and practice of CBC. They are normally

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[65] It is noteworthy that scholars such as Akintola dispute the financial benefits associated with CBC. They argue that insufficient data exists to make such an assumption and that no studies take into account the unpaid labour costs for caregivers and volunteers in CBC.

[66] E. F. Nsutebu et al, "Scaling-up HIV/AIDS and TB home-based care: lessons from Zambia", *Health Policy and Training* 16(3), 2001, pp. 240-247.

[67] R. M. Carelse, *The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS community based care*, MA-Thesis, Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, April 2008, pp. 75-80.

recruited from the unemployed sector in the community and are paid a minimal wage.[68]

- *Single service home/centre based care* is where a single 'service component' (hospital, clinic, church, NGO, etc.) establishes home based care by recruiting, training and supporting CCWs. It strives to establish an effective referral network between CCWs, patients and families. Many CBC programmes are thought to start out this way. As the service expands and incorporates other organisations, it transforms itself into an integrated home community based care service.

- *Informal home based care* has no formal support structure or central organising body that helps administrate CBC. It consists of local community members who care for their own family members within their own social networks. They have little training and support. Care of the patient is based on the caregiver's own knowledge of what is best for the patient. Carelse (2008) regards this model as somewhat impractical, because it leads to isolation of the patient and caregiver, and they lack the necessary support and guidance that could be provided by other role-players.

It seems the integrated approach is considered to be the most useful CBC model.

d. Roles of CCWs

Based on the literature, the following are some of the roles CCWs can fulfil in NGO/CBOs:[69]

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[68] Uys, L. R., "The practice of community caregivers in a home-based HIV/AIDS project in South Africa", *Journal of Clinical Nursing* 11, 2002, p. 100.

[69] R. M. Carelse. The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS community based care, MA Thesis, Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, April 2008, p. 87; T. Colton et al. *Community Home-Based Care for People and Communities Affected by HIV/AIDS*, Pathfinder International, October 2006, pp. 44-46, 113-142, 181-193, 196-230, 251-264; B. Magongo. *Community Health Workers in Gauteng: Context and Policy*, Cadre, 2004, pp. 20-21; N. Mohammed & J. Gikonyo.

- To mobilise the community by, for example, establishing childcare committees, helping identify community needs and identifying support services already in place

- To organise the community and ensure development, by helping ensure an adequate and safe water supply, establishing youth/women's groups, clinics etc.

- To assist community members in the correct treatment of sexually transmitted infections (STIs) and opportunistic infections (OIs), and to educate the community about STIs and OIs

- To provide nursing support for patients at home, such as helping them with bathing, dressing wounds etc.

- To facilitate sexual behaviour change programmes by talking openly about sex, stating the facts about HIV/AIDS, and teaching people about safer sex

- To educate the community about family planning, safe sex and contraceptive methods

- To help distribute condoms

- To play a role in DOT HAART, which is one of the strategies for ART adherence support, by making sure HIV/AIDS patients are taking their medicine correctly and consistently, usually visiting and observing patients directly at their homes. CCWs may also be required to trace patients who missed scheduled ART[70]

Operational Challenges: Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa, African Region Working Paper Series No. 88, August 2005, p. 8; R. Panjabi, et al., *A Community-Based Approach to HIV Care in Rural Liberia: Liberia's HIV Equity Initiative*, Ministry of Health and Social Welfare, Republic of Liberia, November 2007.

[70] DOT, especially where TB is concerned, is not without criticism. Some view the DOT emphasis on 'swallowing' pills as dehumanising and authoritarian. DOT may simply be unsustainable in resource poor settings. Some studies suggest that DOT is no more effective than existing, cheaper treatments for TB, and some view DOT as a failure, because in some areas where DOT was applied, the incidence of drug-resistant TB has risen, instead of decreasing. Consult D. H. S. Tan et al. "Global plagues and

- To play a role in micro credit initiatives or income generation activities

- To provide material assistance to affected families, such as food, clothing, soap, etc. CCWs can also mobilise/educate the community on how to become more self-sufficient where food is concerned, such as creating vegetable gardens

- To assist families that have lost loved ones to HIV/AIDS with funeral arrangements. CCWs can also provide assistance in drawing up wills

- To provide support for HIV/AIDS-affected children, especially orphans and other vulnerable children

- To provide psychosocial support, which includes aspects such as spiritual and emotional counselling, and moral support for PLHA

- To support HIV/AIDS-affected households by assisting them in housekeeping activities, such as collecting firewood, cooking, sweeping, etc.

- To set up effective referral networks, so that PLHA can be referred to the correct medical or other support facility when necessary, and

- To help with record keeping, by noting down the names and addresses of PLHA, keeping note of ART side-effects (if any), and keeping note of other illnesses. They can also help provide information on living circumstances. Effective record keeping will help CCWs and other aid organisations to plan their interventions more effectively and will assist CBC projects in following up on clients.

e. Sustainability

HBC systems are becoming increasingly important in the health care strategies of developing countries, making it essential that CBC programmes are affordable, self-

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the Global Fund: Challenges in the fight against HIV, TB and malaria", *BMC International Health and Human Rights* 3(2), 2003 for more information.

maintained and sustainable.[71] It has been shown that an integrated, decentralised community care approach to HIV/AIDS ART can work in even the poorest rural areas, such as Lusikisiki in the Eastern Cape. ART was significantly enhanced by community mobilisation and the overall health of the community improved, while costs remained unchanged. It must be noted, however, that Lusikisiki is a small community and to reach a wider population, programmes will need outside funding.[72] The larger the project, the more funding is required, and sustainability becomes more of an issue. Despite the importance of sustainability, few sources deal specifically with this subject, especially where South Africa is concerned.

Sadler et al. (2006) list several means of achieving greater sustainability in CBC programmes. They are of the opinion that sustainable CBC requires decentralised systems of monitoring and surveillance that employs a high number of volunteers or outreach staff. A well-planned and co-ordinated strategy is perceived as essential in order to link existing community based interventions and support in order to maximise efficiency. CBC should work through existing health infrastructure and staff, together with developing an effective social network to assist in case-finding, referral and follow-up. To increase the effectiveness of referral even further, it is suggested that one must encourage the community to trust more in local health clinics. Finally, a sustainable source of nutrition for patients in the community is considered important, because importing food is unsustainable in the long term, thus necessitating the development of a local means of food production.[73] Assuring sustainability, therefore, requires the effective use of existing health facilities and setting up a reliable and cheap source of food.

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[71] K. Sadler et al. "Community-based therapeutic care in HIV-affected populations", *Transactions of the Royal Society of Tropical Medicine and Hygiene* 100, 2006, p. 8.
[72] N. Ford et al. "Sustainability of long-term treatment in a rural district: the Lusikisiki model of decentralized HIV/AIDS care", *Southern African Journal of HIV Medicine*, 2006, pp. 17-22.
[73] K. Sadler et al. "Community-based therapeutic care in HIV-affected populations", *Transactions of the Royal Society of Tropical Medicine and Hygiene* 100, 2006, p. 8.

Carelse (2008) suggests that another means of managing the sustainability of CBC programmes is to prioritise the involvement of community volunteers, which will help cut costs. It is believed that HIV/AIDS treatment and care costs drop remarkably when CCWs provide services that would otherwise be paid for by the government, NGOs, etc.[74] Richter et al., using COPE in Malawi as example, say that direct service provision and problem solving within a community is not sustainable. A more sustainable CBC project involves few NGO/CBO staff members, more volunteers, and, more importantly, community mobilisation and capacity building. Instead of addressing the problem directly, it is probably more sustainable to develop the community's own capacities to deal with the problem.[75]

5.2.   Challenges faced and lessons learnt

Mohammed and Gikonyo (2005) provide the most concise description of the challenges faced by CBC programmes. They divide the challenges faced by CBC into three broad categories, consisting of organisation and management, activities and services, and external factors.[76] **Organisational and management challenges** are believed to include the following:

- A lack of human resources, such as insufficient CCWs, limited finance for training, lack of counselling and support for CCWs, and lack of managers

- Limited institutional resources, which includes aspects such as lack of transportation for CCWs, few CHBC medical kits, insufficient educational supplies and technical kits, poor logistics, and limited funds, and

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[74] R. M. Carelse. "The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS community based care", MA Thesis, Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, April 2008, p. 82.

[75] L. Richter et al. *Family and Community Interventions for Children Affected by AIDS*, Human Sciences Research Council, Cape Town, 2004, pp. 45-46.

[76] N. Mohammed & J. Gikonyo. *Operational Challenges: Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa*, African Region Working Paper Series No. 88, August 2005, p. 11.

- Poor referral system/linkages, referring to inadequate co-ordination of CHBC activities between CBOs and health facilities, lack of referral and counter-referral with health facilities regarding PLHA medical treatment.

Challenges found under the heading **Activities and services** include:

- Inadequate ART support. Biological tests that monitor ART adherence are expensive and therefore neglected. Counselling is considered time-consuming and as a result, this aspect of ART is often neglected

- Lack of proper nutritional support for PLHA. Limited food security programmes and inadequate knowledge of the proper nutritional care of PLHA constitute the main concern

- Limited socio-economic initiatives for generating income for PLHA. This can lead PLHA to turn to sex work as a means of generating income

- Limited support for orphans and vulnerable children (OVC), especially where nutrition and organisation is concerned

- Stigma and discrimination. Indeed, Sadler et al. (2006) regard stigma in such a serious light that they propose that CBC should be introduced into some communities under the guise of 'nutritional support and care'. Once some form of trust is established, then an organisation can move to HIV/AIDS focussed CBC[77], and

- Lack of proper health education, especially where the nutrition of PLHA is concerned, as well as knowledge pertaining to the treatment of side-effects of ART.

Where **external factors** are concerned, Mohammed and Gikonyo (2005) identified the following challenge:

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[77] K. Sadler et al. "Community-based therapeutic care in HIV-affected populations", *Transactions of the Royal Society of Tropical Medicine and Hygiene* 100, 2006, p. 8.

- Medical supplies and health facility proximity challenges. This means that if there is no nearby provider for a service or product, then a CBC programme may run into serious logistical problems.

Managing volunteers, moreover, can prove difficult. Russel and Schneider (2008) state that recruiting and maintaining commitment from volunteers is one of the main challenges facing CBC. Many CBC projects report a high turnover of volunteers. Once trained, many volunteers move on to other opportunities, drop out or prove unreliable. The problem is that it is unsustainable in the long run to provide a significant stipend to volunteers. Non-financial incentives are therefore necessary to motivate volunteers, such as a sense of belonging, a supportive work environment, opportunities to gain skills and passing a thorough screening process.[78] High turnover of volunteers seems to be a significant problem in South Africa. Gauteng province had a policy in 2004 that volunteers should be paid a minimum stipend of R500 to help prevent high turnover rates.[79] In addition, CCWs have personal problems.

According to Akintole (2008), CHWs face the following challenges:[80]

- They are under severe emotional strain (witnessing discrimination and stigma towards PLHA; dealing with clients' conditions; pressure to learn new skills quickly, frustration, etc). They cope by increasing efforts to educate family members, making peace with the terrible physical state of some clients, focusing on becoming competent caregivers, taking their minds off the situation, talking to colleagues or religious professionals, or attending church.

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[78] M. Russel & H. Schneider. "Chapter 16: Models of community-based HIV/AIDS care and support", in A. Ntuli (ed), *South African Health Review 2000*, Health Systems Trust, 2000, p. 332.

[79] B. Magongo. *Community Health Workers in Gauteng: Context and Policy*, Cadre, 2004, p. 17.

[80] O. Akintola. "Defying all odds: coping with the challenges of volunteer caregiving for patients with AIDS in South Africa", *Journal of Advanced Nursing* 63(4), pp. 360-362; L. De Saxe Zerdin et al. "Caring for home-based care workers", *The Southern African Journal of HIV Medicine*, September 2006, pp. 38-43.

- Problems related to confidentiality. Clients often insist vehemently that their serostatus remain secret, even in their medical files. CHWs are consequently under severe pressure to maintain confidentiality and this impacts negatively on their work and the health of their clients. They cope by using secret codes that only they understand to indicate on a client's file that he/she is seropositive.

- Sometimes volunteers have to deal with emotional outbursts and unreasonable behaviour from their clients and the clients' families. CHWs cope by attributing these behaviours and outbursts to the illness, and family members are educated to understand the CHWs' capabilities and limitations.

- They are confronted daily by poverty. The effort to provide families with food and access to social welfare grants takes its toll.

- CHWs are often mocked or insulted by friends and family members, because they do not earn an income from their volunteer work. In response, CHWs develop a 'thick skin' and criticism from family and friends often help CHWs to re-evaluate their motivations for doing volunteer work.

5.3.   Benefits arising from AFSA involvement

As an enabling organisation, AFSA's work benefits its partner organisations in a variety of general ways (see 5.3a below). Firstly, AFSA assists its partner organisations to be secure in their funding, and thus able to focus on project implementation to the exclusion of distractions. [81]

Secondly, AFSA's work goes a long way towards enabling partner organisations to competently plan, and monitor and evaluate their respective projects. AFSA has created a simplified version of the logical framework analysis (LFA) tool with descriptors and explanations of concepts, to assist CBOs in developing logical and

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[81] See Section 2 b of this report (above) for further discussion.

measurable work plans. Project officers work with new and weaker CBOs to assist them with the development of their work plans and budgets.

AFSA has also developed checklists and forms for use by CBO personnel and community care workers, to assist CBOs to gather and record data during the project term. Such data is submitted to AFSA on a quarterly basis along with progress reports. AFSA project officers, as a minimum requirement, conduct quarterly site visits to each of the CBO partners to monitor the progress of work being carried out, review data collection, check financial accounts, and provide onsite mentoring and coaching. In the case of weaker CBOs these visits take place more frequently, and as often as every second month if necessary.

Thirdly, AFSA aids its partner organisations in attaining the necessary skills to make effective community responses. This is important because community responses are critical in helping stem the tide and dealing with the 'fall out' of HIV and AIDS. However, without a focused and sustained programme that imparts relevant skills and enhances the competencies of community organisations, well-intended efforts may not necessarily achieve the desired results.

This means that capacity building is not only about training workshops, but also forms part of a broader intervention of mentoring, technical support and monitoring the application of skills taught and work performed through regular site visits to beneficiary community organisations. AFSA's capacity building interventions seek to address skills deficiencies and competencies on two levels: project implementation and service delivery, and organisational development and governance.

AFSA is an accredited training service provider registered with the Health & Welfare SETA. AFSA provides accredited training (or utilises the services of external service providers) for HIV and AIDS counselling, ancillary health care work, child and youth care work, early childhood development, and auxiliary social work. AFSA also hosts a biennial 'Learning and sharing conference' for all its partner organisations.

AFSA facilitates two learning community networks: one for CBO partners implementing specialist OVC interventions and the other for partner organisations supported through its Culture and Health Programme. Non-accredited skills building workshops and onsite mentoring and coaching for partner CBOs cover project planning, monitoring and evaluation, basic bookkeeping and financial record keeping, governance development of human resource policies and job descriptions for CBO employees and volunteers, and periodic workshops to assist CBOs to prepare and submit funding applications to the National Lottery and government departments.

AFSA's work is not only limited to 'general' benefits arising from the involvement of enabling organisations. Evidence presented earlier in this report has already indicated the impact of AFSA on CCWs and volunteers (see, for example, sections 2(b) and 4(c) above). AFSA not only provides volunteers with work-related training, but also does its best to see that they are stipended through their partner organisations, and that they get the necessary psycho-social support.

a. General benefits

Taking account of the vast range of activities a potential CBC can be involved in, it is apparent that CBC programmes can benefit from outside support. Mentoring or enabling organisations can consist of official government committees created to support CBC programmes. The type of mentoring/support provided by a small NGO to a CBC project will differ substantially from support made available by larger NGOs which may support several different projects.

Before outlining the various roles these external or enabling organisations fulfil in CBC, it would be useful to first look at what the literature regards as unsuitable behaviour for enabling organisations. According to Richter et al. (2004), an enabling organisation should not undermine the emergence and sustainability of CBC

programmes. There are various ways an enabling organisation can hinder CBC programs[82], for example:

- By diverting the agenda of community actions. This occurs if the enabling organisation forces its own policies and preferences onto its beneficiaries. This is a mistake large enabling NGOs may make, but even smaller NGOs can do this.

- Through inappropriate targeting of specific risk groups, which leaves other groups unsupported and which could lead to resentment between the beneficiaries and those left out. For example, targeting only PLHA while ignoring other chronically ill patients.

- Through providing direct outside material support, which can disrupt community actions or reduce the community's sense of responsibility.

- Through the enabling organisation taking on too much responsibility for CBC, and running the risk of leaving the community worse off, because once the enabling organisation's participation inevitably ends, the community may have lost its spontaneity and initiative to take positive action on its own behalf. This appears to be a mistake more often made by small NGOs closely involved with a specific CBC project.

- Through enabling organisations providing material and financial support directly to families. When providing material support, it should be through CCWs. Providing material support on a large scale, however, is too expensive in the long term and will only benefit a small number of people in a community.

The literature gives the impression that the best way for enabling organisations to support CBC is through actions such as financing, training and capacity building. Russel and Schneider (2000) place a strong emphasis on technical assistance and

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[82] L. Richter et al. *Family and Community Interventions for Children Affected by AIDS*, Human Sciences Research Council, Cape Town, 2004, p. 19.

capacity building for CBOs. It is argued that developing simple management systems may be of greater value than direct financial support. Activities such as identifying and mobilising existing community resources, mobilising financial and material resources, programme management and building skills in service provision ought to be the main task of enabling organisations.[83] Most of the literature supports this view. Based on the work of Richter et al. (2004), Mohammed and Gikonyo (2005) and Thurman et al (2007)[84], the following roles were identified:

- Raising awareness about the impact of HIV/AIDS on communities

- Community mobilisation by encouraging the community to provide vulnerable members with care and support

- Strengthening community networking by helping CBOs use local resources more effectively. It is also important to help CBOs develop an effective referral network. Large NGOs are particularly suited to this purpose

- Training and capacity development. Capacity development can be defined as "the ability of individuals or organisational units to perform functions effectively, efficiently and sustainably"[85]

- Human resource support, such as providing administrative staff or technical staff, volunteers, workshops, paying salaries, technical assistance, etc. Larger NGOs probably play a more important part here

- Strengthening institutions and developing systems

- Supporting the collection and analysis of data collected in communities

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[83] M. Russel & H. Schneider. *A Rapid Appraisal of Community-based HIV/AIDS Care and Support Programmes in South Africa*, University of Witwatersrand, Johannesburg, January 2000, pp. 35-36.
[84] N. Mohammed & J. Gikonyo. *Operational Challenges: Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa*, African Region Working Paper Series No. 88, August 2005, p. 9; L. Richter et al. *Family and Community Interventions for Children Affected by AIDS*, Human Sciences Research Council, Cape Town, 2004, pp. 19-20; T. R. Thurman et al. *A Case Study: Community-Based HIV/AIDS Prevention, Care, and Support Program*, MEASURE Evaluation and Pathfinder International, 2007, pp. 16-22.
[85] M. Godfrey et al. *Technical Assistance and Capacity Development in an Aid-dependant Economy: the Experience of Cambodia*, Phnom Penh, 2000, p. 7.

- Disseminating examples of good practice. Large NGOs with their extensive networks and contacts are ideal in this case

- Linking communities with appropriate sources of support

- Monitoring and evaluation of CBC

- Advocacy on behalf of HIV/AIDS-affected groups, and

- Material support, such as providing incentives to volunteers, small grants for projects, food, clothing, training manuals, prescription drugs, guidelines on ART adherence, equipment, etc. Larger NGOs with more resources available can do this.

b. Benefiting CCWs

According to the literature, there are several ways in which NGOs/CBOs and other organisations can help support CCWs:[86]

- Mental health care nurses and psychosocial workers should be involved from the start. In this way, CCWs learn early on how to cope with the various stresses they will be facing. Psychosocial support should, however, be continually available

- Nurses should work more closely with CCWs in a team in order to provide a continuum of care for PLHA. It is unreasonable to expect CCWs to care and treat PLHAs on their own without professional assistance from nurses and other health professionals

- People in current support roles in the community, such as clergy, church members and other volunteers, should be trained to offer emotional support for CCWs

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[86] O. Akintola. "Defying all odds: coping with the challenges of volunteer care giving for patients with AIDS in South Africa", *Journal of Advanced Nursing* 63(4), pp. 363-364; L. A. Christensen et al. "Aspects of motivation of a volunteer AIDS care team program", *AIDS Education and Prevention* 11(5). 1999, pp. 427-435; L. De Saxe Zerdin et al. "Caring for Home-Based Care Workers", *The Southern African Journal of HIV Medicine*, September 2006, p. 43.

- Social services staff could help CCWs in obtaining welfare grants for clients. They can also assist CCWs to get food and other supplies to families who are unable to access welfare grants

- The poor mental and physical health status of clients can be a source of stress for CCWs. It would appear that CCWs are often badly treated by clients. It is suggested that CCWs can be supported by providing mental and health treatment to clients

- The lack of proper transport is sometimes cited as a major problem for CCWs, who are unable to reach clients in time, and this makes the transport of critically ill patients to a clinic/hospital difficult. Therefore, it may be a viable support strategy to provide transportation facilities/vehicles to CCWs

- CCWs regard training as very important. It has been suggested that providing rotating training schedules will allow CCWs to finish their training, while not neglecting their clients, and

- CCWs apparently find weekly team meetings helpful. Organising and co-ordinating these meetings could help support CCWs.

5.4.   Possible further government involvement

a. The role of government

Richter et al. (2004) believe that there are a few key areas where the South African government ought to support CBC programmes. Although Richter et al. focus mostly on CBC for orphans and vulnerable children;[87] the authors' expectations of government involvement can easily be applied to more general CBC programmes. Government is expected to:

- Take the lead in broadening the response to HIV beyond the formal health sector

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[87] L. Richter et al. *Family and Community Interventions for Children Affected by AIDS*, Human Sciences Research Council, Cape Town, 2004, p. 53.

- Expand interventions to the scale required to meet the level of demand, because NGOs are unable to bear the burden alone

- Enact policies to respect and protect the rights of children, PLHA and other disadvantaged groups to health, nutrition, education, inheritance and protection from abuse

- Create infrastructure at district level to enable the local government to support community initiatives

- Prohibit discrimination and stigma

- Provide accessible information

- Provide services and training on HIV-related issues for government staff whose jobs intersect with the care of children, PLHA, etc.

- Encourage and support NGOs and private sector involvement in CBC. This seems an important function of the state. Ncama (2005), for example, cites a study conducted in South Africa that reveals that CBC programmes have difficulty communicating with, maintaining relationships with, and receiving support from larger NGOs. Many CBC programmes in South Africa require external support to aid caregivers and communities, but they seem to have difficulty promoting and sustaining partnerships with large NGOs, both nationally and internationally[88]

- Lead and co-ordinate the activities of donors, NGOs, and the rest of civil society in CBC, and

- Develop and implement a monitoring and evaluation mechanism to ensure that CBC programmes adhere to the guidelines and policies of government,

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[88] B. P. Ncama. "Models of community/home-based care for people living with HIV/AIDS in Southern Africa", *Journal of the Association of Nurses in AIDS Care* 16(3), May/June 2005, p. 39.

especially where legal and human rights are concerned (based on Mamaila (2005).[89]

b. Criticism of government

Lack of government involvement in CBC is often a point of criticism. Kautzky and Tollman (2008), for instance, seem to regard the government's efforts at establishing PHC (and hence more effective and comprehensive CBC) in South Africa as a failure. There are a variety of reasons listed, including administrative problems, lack of leadership, lack of commitment from politicians, a shortage of health worker personnel, deep-seated imbalances in resource distribution, the HIV/AIDS epidemic (which overburdens the health sector and demoralises it), and a curative-orientated health service. Where CBC in post-apartheid South Africa is concerned, the most important failure listed is the government's failure to enlist the participation of civil society into the process of implementing PHC.[90]

Richter et al. (2004), Mamaila (2005), Ncama (2005), Friedman et al. (2007) and Akintola (2008) mention several problems in the relationship between government and civil society:[91]

- Most CBC programmes in South Africa are funded by national and international donors. If these funds dry up, many CBC programmes will be unable to continue. In some cases, donors refuse to pay salaries for caregivers, leaving CBC projects totally dependent on unpaid volunteer work.

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[89] T. Mamaila. Community-based care for HIV/AIDS orphans, MA-thesis in Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, May 2005, p. 88.

[90] K. Kautzky & S. M. Tollman. "A perspective on primary health care in South Africa", School of Public Health, University of Witwatersrand, 2008, pp.23-25.

[91] O. Akintola. "Defying all odds: coping with the challenges of volunteer caregiving for patients with AIDS in South Africa", *Journal of Advanced Nursing* 63(4), p. 358; I. Friedman et al. *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes*, Health Systems Trust, 2007, p. 4; T. Mamaila. Community-based care for HIV/AIDS orphans, MA-thesis in Faculty of Humanities, Department of Social Work and Criminology, University of Pretoria, May 2005, pp. 36-40; B. P. Ncama. "Models of community/home-based care for people living with HIV/AIDS in Southern Africa", *Journal of the Association of Nurses in AIDS Care* 16(3), May/June 2005, pp. 33-34, 37-39; L. Richter et al. *Family and Community Interventions for Children Affected by AIDS*, Human Sciences Research Council, Cape Town, 2004, pp. 53-54.

This means that government should help construct infrastructure, provide funding, become more actively involved in capacity building, co-ordinate the efforts of different CBOs and NGOs, assist in obtaining funds from donors, assist in education endeavours, etc.

• The government has no monitoring or evaluation structures in place for CBC. Despite their enthusiastic endorsement of CBC, the government has no means to determine to what extent CBC programmes are contributing to the overall National Health Plan strategy, and there are no mechanisms that monitor whether CBC programmes are respecting the rights of vulnerable groups, such as AIDS orphans, and

• In South Africa, each province responds differently to CBC programmes. There is no central strategy for the country as a whole. In practice, this means that relatively wealthy provinces such as Gauteng provide adequate support to CBC programmes and even have staff dedicated to maintaining relations with NGOs and CBOs. In other provinces, however, support is less forthcoming.

c. What government expects

According to government guidelines on CBC, it is clear that CBC is regarded as a holistic approach and that different stakeholders should be involved in providing and managing CBC in South Africa. Governmental expectations of civil society in many respects mirror what civil society expects from government:[92]

• Identify community needs and priorities, including financial needs

• Provide outreach to members of communities

• Provide operational coordination, planning and collaboration

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[92] Department of Health. *National Guideline on home-base care/community-based care*, South Africa, 2001, pp. 6-8.

- Monitor and evaluate service patterns, quality of care and consumer satisfaction

- Ensure optimisation and control of available resources

- Provide advocacy and lobbying for services and resources, as well as advising the formal health system

- Negotiate with other sectors

- Developing sustainable care programmes

- Provide direct care - preventative, curative, therapeutic, rehabilitative and palliative

- Provide capacity building and support to caregivers

- Provide leadership

- Identify consumers and service providers

- Deal with suspected abuse, and provide disciplinary measures and complaints, and

- Provide referral systems.

6. Recommendations regarding a model or framework

The idea or concept of 'best practice' came into its own with UNAIDS, which publishes a collection of 'best practice models'. This collection aims to promote learning, sharing of experience and empowerment of partners, including people living with HIV, affected communities, civil society and governments, the private sector and donors.

UNAIDS provides information about what has worked in particular settings to inform others working in similar settings and facing similar challenges. In more recent times, there has been a move away from best practice to the use of the term 'promising practice' or 'effective practice'. In short, UNAIDS attempts to highlight what has

worked and why and where programmes may have failed, and why this should be the case. On the whole best practices have four common characteristics: (1) they are innovative, (2) they make a difference, (3) they have a sustainable effect, and (4) they have the potential to be replicated and generate a model that can be used for developing initiatives elsewhere. When reviewing the success of AFSA-funded CBOs these four characteristics should become part of the M & E guidelines.

However, there is also the danger that attempting to develop best practice or models of intervention can lead to unrealistic expectations and a sense of failure when implementation fails to reach the goals set out in the model or practice. The model of intervention can become a means by which community based work can be disciplined, governed and regulated. Very often the hope for models for intervention locks responses into narrow boxes. Best practice and the development of models run the danger of jeopardising our ability to see the world as it is, as well as our ability to offer constructive ideas about how to change it. Models inevitably end up trying to fit the subject to the technology rather than the other way round.

As the Friedman model so clearly shows, there is the danger that models become 'ready made' or 'ready to use' and are dependent on a range of structural conditions being in place before implementation is possible. The Friedman model highlights many of the aspects emphasised in this research but it fails in the end, in that it lacks sufficient flexibility to meet the very exacting and diverse needs of the communities most at need of community based care and support.

There are many models of community based care – but as the introduction highlights, these often do not take into account the specific circumstances under which people are living and the idea of a best practice or model runs the risk of homogenising different communities and groups.

Community based care is based on five generally accepted pillars: (1) primary care, (2) prevention of illness, (3) health promotion, (4) community capacity building and (5) service integration. Each of these pillars can and should be assessed under the four UN categories (mentioned earlier). These allow for different CBOs to concentrate on the areas in which they do best, and to gain the support and

expertise from other CBOs working in the area, e.g. a CBO engaged in home-based care may not have the capacity to develop a nutrition programme but will be able to link with a CBO in the same area involved in nutrition, and they can mutually strengthen and support one another. All CBC interventions need to ensure that they are comprehensive, accessible, holistic and integrated, and where possible, community governed and grounded in community development and strengthening.

It is vitally important that government and civil society interactions with CBOs are sensitive to local contexts if these organisations are to operate successfully. Since contexts are hardly ever static, ways of interaction should be flexible and able to change as contexts shift. Models, such as those proposed by Friedman,[93] are too rigid – due to their very nature – for this to be achieved.

Evidence presented in this report indicates that a *process* rather than a model may indeed provide a possibility of effectively structuring such ways of interaction. The process proposed here will include the following elements:

- Prior to applying for funding to set up a CBO , or as a condition of first or renewed funding for a CBO, the person/s aiming to get a CBO off the ground, or the management of the CBO applying for funding, should conduct an audit of needs, services and resources at community level. This audit should involve as many role players as possible: the individuals starting or running the organisation, gatekeepers and opinion leaders in the community, relevant local (or if appropriate, provincial) government departments (health, social welfare, agriculture and education), existing state and private health care providers, other CBOs and NGOs in the community, and other relevant civil society providers of services (such as faith-based organisations, local social movements, cultural organisations, traditional healers) and, where possible, traditional local leaders. AFSA should play a role in initiating and funding these audits in collaboration

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[93] I. Friedman *et al*, *Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes,* Health Systems Trust, September 2007.

with other organisations which are working in the community. This audit should be repeated on an annual basis to ensure that outcomes are in line with agreed indicators, measure up to the UNAIDS categories and address the five pillars of CBC.

- Based on these findings:
  - There should be agreement to initiate or continue with forums in which all role-players are represented
  - Agreement should be reached with regards to the roles and responsibilities of different role-players (government and civil society), so that unnecessary overlap between role-players is eliminated and good referral mechanisms are facilitated, to reduce tensions from competition for scarce resources
  - There should be a decision on the goals and objectives of the CBO as well as indicators for monitoring and evaluation, and
  - There should be agreement on capacity building needs, and this should be used as the basis for securing funding. There should also be agreement on developing diverse sources of funding and broadening the funding base of a CBO
- Agreement should also be reached on:
  - Whether or not a CBO needs a board, and the relationship between the board and the management of the CBO
  - The ratio of staff to volunteers
  - Skills needed (including future skills) – this should include skills on financial management, project management, networking, marketing and fundraising
  - Support needs of staff and volunteers – where relevant these can be provided by local providers (both government and civil society)
  - How volunteers will be recruited and paid
  - How volunteer career paths may be linked to accredited training packages
  - How volunteer work may be incentivised through recognition and affirmation in the community, and

- o The issue of accreditation needs to be championed and researched by a mentoring organisation such as AFSA – accreditation should be relevant in a specific local context, and
- All decisions taken in the forum and within the CBO must be documented and used as a basis for reporting and regular review, with a larger annual review to promote better decision making.

The steps outlined above resonate with and can be seen to supplement AFSA's Four-Step Activity Plan that has as its aim to strengthen civil society for effective intervention in the HIV and AIDS epidemic. This will be achieved by (1) assessing and contracting partner organisations, (2) providing financial support and developing the capacity of partner organisations, (3) monitoring and evaluating the work of partner organisations, and (4) accounting and reporting to the donor.[94]

In the contracting of partner organisations, AFSA needs to think about whether it is more feasible to achieve greater geographical coverage by engaging with more partner organisations and broadening the approach to HBC, or whether it is better to establish closer relations with committed partners in fewer geographical areas so as to develop services for vulnerable groups affected by HIV/AIDS. There are pros and cons to each option. The former would need a larger staff compliment, so the organisation would need to recruit more staff members. It would also entail a larger budget. The latter could be implemented with present staff resources and an operational plan and a budget could be developed. It would build on the experiences of the past and consolidate the gains in a limited number of geographical areas. At the end of such a project the network of partner organisations should be sustainable.

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[94] AIDS Foundation of South Africa (AFSA). Strengthening civil society for effective intervention in the HIV and AIDS epidemic, Request for funding from the Atlantic Philanthropies, 30 September 2009.

7. Conclusion

The findings in this report are not substantively different from those presented by Friedman.[95] They also resonate with most of the extant literature summarised above. Evidence suggests that the recruitment and management of volunteers stand central to CBO efficacy. In this enabling organisations and government are key role-players in terms of funding, training and support.[96] Just as importantly, CBOs need to be sensitive to, and structured around the needs of the communities they serve. Community involvement is thus vitally important, and active participation from community members should be encouraged at all times.

The field research, while it highlighted many fascinating similarities across CBOs and regions, also showed the importance of local context. What this means is that implementing any 'model' or 'best practice' looking to cover work in diverse communities, with differing relations to traditions, modernity, superstition and beliefs, is problematic. A model can be developed but the implementation then becomes context-specific – meaning that the model needs to be able to accommodate many social, cultural, economic and historical variables.

Furthermore, the literature and the findings presented in this report agree that HCBC should be integrated. The most effective CBOs are holistic in their approaches and, in addition to HBC, offer programmes aimed at, or partner with organisations that address, issues related to poverty alleviation, skills and capacity building, etc. Here, again, enabling organisations and government have key roles to play.

The question that begs itself is: how does one structure government/civil society interaction with CBOs so as to achieve maximum efficacy? It is the opinion of this research team that best practice *models* such as Friedman's – especially given the fact that they are frequently conceptualised as organograms – are far too rigid to

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[95] I. Friedman *et al. Moving Towards Best Practice: Documenting and Learning from Existing Community Health/Care Worker Programmes,* Health Systems Trust, September 2007.
[96] Payment of volunteers is a fundamental issue that needs attention by funders and government alike, along with addressing concerns about CCW training and certification.

cope with and adapt to the ever changing circumstances within which CBOs find themselves. Therefore a flexible *process* that moulds itself to local contexts has been proposed in its stead. In the main this process resonates with and adds to AFSA's four step activity plan outlined above.

The CBOs visited in this research were more or less successful, depending on how well they understood the process outlined. A process allows for CBOs to move in different time-frames and to adapt and change as local conditions demand. Models or best practice tend to assume that all kinds of structures would be, or would need to be, in place in order for the model to work and that failure would be measured against set indicators and time-frames. Working through an AFSA- facilitated process allows for CBOs to constantly reflect and refine, and to develop skills and capacity while developing interventions that work and can be sustained.

Other CBOs can learn a great deal from understanding how such a process works, and ensure that the interventions they develop are innovative, accumulative, based on past experiences and insights, and have a demonstrable and a tangible impact on improving the quality of life. They also create channels for effective citizenship and participation and partnerships and enhance community understanding of ***what is*** as well as ***what could be.***

In conclusion, any notion of a 'best practice' or model must be able to answer the following questions:

1) Is the work being done innovative, building on past experience but not doing more of the same?

2) What difference will the organisation make not only to the health and community-related needs of the people they reach, but also how those people think about CBC and what they can expect to receive from civil society and the state?

3) What is needed to make the programme sustainable? Is it realistic in the current financial and political climate to expect community-based sustainability or should long-term funding (over five years) be provided?

4) To what extent can this particular project or programme be implemented, adapted or altered for other regions?

Best practice or a model is not the replication of one good system, one good project or one good funding mechanism, but rather a critical process that clearly understands and critiques 'failures' as a crucial element in developing interventions and a critical process that over time and across projects evaluates what works, taking into account the individual, social and structural contexts in which interventions take place. The process outlined in this report requires that what needs to be central and ongoing is critique and critical evaluation of how funding has worked, what has led to success and failure, and what might be the basis for promoting effective interventions. AFSA has a unique opportunity to develop and promote such a critical process through critique and understanding leading to new ways of seeing and understanding CBC.

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