Global HIV/AIDS Initiatives Network - GHIN

The evolution and sustainability of Community Based Organisations providing HIV and AIDS services in Zambia – lessons from Mumbwa district

Policy Brief – May 2011

Key messages

Findings from this study highlight the importance of retaining and supporting a specific community response to HIV and AIDS, rather than relying on a generic poverty alleviation approach to meet the needs of people living with HIV and AIDS (PLWHAs). Poverty is both a determinant and a frequent outcome of HIV and AIDS, but can be targeted directly through essential care and support services such as home-based care, treatment adherence support, counselling, transport to health centres and nutritional support. Specific recommendations include:

- Conduct a comprehensive situation analysis of community-based AIDS care and support services and needs within each district. Funding for care and support should be based on valid and reliable estimates of service need and coverage gaps.

- Where funds to support HIV and AIDS care and support activities at the district and community levels are currently available, the existence of funding sources and mechanisms for accessing them need to be communicated much more effectively to CBOs. Funders also need to make their funding conditions more explicit to CBOs and other potential recipients.

INTRODUCTION

Community Based Organisations (CBOs) provide important advocacy, care and support services for people living with HIV and AIDS in Zambia. A study commissioned by the National AIDS Council of Zambia (NAC) found that between 2006 and 2008, civil society organisations (CSOs - taken to include CBOs) provided around 30% of voluntary counselling and testing (VCT) services, 80% of treatment, care and support services, and 70% of support services to orphans and vulnerable children (OVCs) (Macintyre and Carey, 2009).

Launched in 2000, the World Bank Multi-County AIDS Program in Africa (MAP) was the first Global Health Initiative (GHI) to fight HIV and AIDS, and it laid the foundations for the large scale-up in external funding for the disease during the following decade (Ndubani et al, 2009). A pre-condition to qualify for MAP funding was that countries must disburse 40-60% of MAP funds to CSOs. In Zambia, MAP funding was the first large-scale attempt to fund the community effort to respond to HIV and AIDS. The World Bank provided the Zambian Government with a grant of US $ 42 million to support the National HIV/AIDS Intervention Strategic Plan 2001-2005 through the MAP-funded Zambia National Response to HIV/AIDS (ZANARA) project between 2003 and 2008.

Funds were disbursed by ZANARA to all the line ministries. 35% of MAP commitments in Zambia went to the Community Response to AIDS (CRAIDS) project. In 2003 ZANARA funded 22% of the national response to HIV and AIDS control. By 2005 this had reduced to 9% of the response as support from the Global Fund to Fight AIDS, TB and Malaria (Global Fund) grew, and down to just 1% at ZANARA's close in 2008 when the President's Emergency Plan for AIDS Relief (PEPFAR) became the major funder of HIV and AIDS control activities in Zambia (World Bank, 2009). In 2008, the World Bank offered a loan of US $20 million to the Zambian Government as a follow-on to the earlier grant. Zambia no longer qualified for a grant due to the completion of the Heavily Indebted Poor Country (HIPC) Initiative. The Government rejected the loan offer and the grant ceased at the end of August 2008.

STUDY BACKGROUND

The aim of this 2010-11 study was to assess the impact of the cessation of the World Bank Multi Country AIDS Program (MAP) on HIV and AIDS care and support activities and on the sustainability of CBOs working in this field at the community level in Mumbwa rural district of Zambia. Objectives included assessing the impact of the cessation of World Bank funds on MAP-funded HIV and AIDS CBOs':-

- ability to raise alternative funds
- ability to continue activities or provide services
- organisational capacity
- participation in district coordination and planning of HIV and AIDS programmes and services

All CBOs in Mumbwa district that had received CRAIDS funding were interviewed (n = 18). District level interviewees included representatives of the District AIDS Task Force, Mumbwa District Council and Mumbwa District Commission, and representatives from the Community AIDS Task Forces (n =10). Interviews were conducted with key national stakeholders including senior representatives of government ministries and agencies, and of bilateral and multilateral development agencies (n = 11). A draft of the report summary and recommendations was tabled at a dissemination meeting in Lusaka on 2 March 2011.

RESULTS

FUNDING

Funding pre-CRAIDS and the CRAIDS era

All 18 Mumbwa CBOs existed prior to receiving CRAIDS grants, some as early as 1992. This is contrary to the perception from some national level respondents that CBOs in Zambia emerged and were established in order to access CRAIDS funds, without proper plans in place to serve the community of people living with HIV and AIDS. Nine CBOs had no external funding prior to CRAIDS. They survived primarily from: animal rearing, farming and other income generating activities (IGAs) such as knitting, sewing and cooking, as well as through their own donations for membership and fundraising.

Most CBOs heard about CRAIDS funding through the District AIDS Coordinator (DACA) and the CRAIDS regional facilitator. Some CBOs reported that there had been delays in the receipt of CRAIDS funds The size of grants per organisation ranged from K38 million (US $8,000) to K72 million (US $15,000), which they received in payment vouchers or cheques. Although the initial target was to fund 350 projects, CRAIDS funded 1,800 community initiatives (World Bank, 2009).

In general CRAIDS funding was viewed positively by most of the CBOs in Mumbwa. It did not impose the conditions that other sources of funding required, such as audited accounts, which made funding more accessible. The principle requirement was that CBOs register and open a bank account.

However, conditions specified which services were to be provided. Many of the CBOs were unhappy with these and not all received funding for the services for which they applied. District and national level respondents attributed these requirements on CBOs to change the focus of their planned activities to the need to prevent duplication of services in the district and to ensure that there was a proper distribution and availability of services across the district. There was a general awareness amongst CBOs that CRAIDS funding was available for a limited time period only. However, some CBOs said they were given no notice and that CRAIDS ceased abruptly, giving them no time to put alternative funding plans in place.

The current funding gap

There was consensus among interviewees that the funding opportunities for CBOs in Mumbwa in late 2010 were scarce and had decreased since the end of CRAIDS in 2008. Most CBOs were not aware of other sources of funding that they could apply for. However, despite the funding gap, most interviewees believed that the support systems and linkages that they had established with the support of the CRAIDS funding had remained strong at the community level.

A number of CBOs voiced a perception that the Zambia National AIDS Network (ZNAN), the civil society umbrella body funded by the Global Fund, made it difficult for communities to access funds. Reported conditions were that an organisation must be a member for at least three years, and needed to have an audited bank account to qualify for funding. However, it was clarified by ZNAN that this was not the case for their micro and small grants, where the eligibility criteria were that an organisation must be in existence for one year, be registered as an organisation, have a governance structure and an updated bank account. In 2010, there was little knowledge of the US Presidents Emergency Plan for AIDS Relief (PEPFAR) amongst CBOs in Mumbwa, or of the different grants that PEPFAR currently provided which CBOs would be eligible to apply for.

The Ministry for Community Development and Social Services (MCDSS) funding scheme to support OVCs was reported by some national respondents as ineffective. District and community level respondents did not mention this scheme, which suggests they were unaware of it. The social cash transfer scheme was another avenue through which some people living with HIV and OVCs were reported to be benefiting directly, though the scheme was being rolled out slowly.

CBO SERVICE PROVISION
Services provided by CBOs include:

- Home-based care – nutritional support, counselling, cleaning and washing, delivering food.
- Transport (mainly bicycles) for promoting ARV adherence, travel to the health centre and for home-based care.
- Sensitisation activities by volunteers for HIV prevention and to reduce stigma and discrimination, including youth drama groups and awareness campaigns.
- OVC support: subsidies for nutrition support (mainly school meals), school uniforms, school fees, and home-based care.

CBOs are the most active providers of care and support services for HIV and AIDS in Mumbwa. World Vision and Child Fund also deliver care and support services, but with defined catchment areas that cover only parts of the district.

Effectiveness and sustainability of Income Generating Activities

CRAIDS funding has given CBOs in Mumbwa the opportunity to become sustainable, and most have engaged in IGAs to enable or to boost service provision. These consisted of the rearing of poultry, pigs and goats; as well as vegetable and crop farming, cooking, knitting and sewing.

Provision of a hammer mill, mainly to mill maize, is one of the main IGAs in Mumbwa, although some CBO representatives reported that they generated little profit, due to frequent break-downs and the lack of resources to repair them. Other IGAs such as farming, and animal rearing were mentioned as not being sustainable. Only two CBO representatives reported that the IGAs that they established had enabled them to maintain their level of HIV and AIDS support services.

A number of respondents at all levels were of the view that more money should have been invested by CRAIDS in IGAs and that sustainability plans were generally weak. Some groups did not have adequate nearby markets and roads and bridges in the area were often poor. This often meant depending on the small markets within the village. It was reported that too many similar IGAs exist in a small geographical area, creating too much competition amongst organisations.

Current gaps in services due to CRAIDS cessation

While all CBOs were still functioning at the time of community interviews in mid 2010, most reported reductions in service provision. The biggest obstacle, reported by all CBOs, was the lack of transport – for Home-Based Care (HBC) givers, for ARV adherence support, for HIV counselling, and to bring patients to the hospital/clinics. While CRAIDS funding had provided bicycles, many of these were now beyond repair, resulting in some HBC givers walking for up to 10 kilometres to reach their clients.

A large decrease in nutritional support for schools was reported, and had been cut completely in two schools. This had resulted in children dropping out of school.

"For the vulnerable and orphans there is a slight change because when CRAIDS was funding us there was a feeding programme. Right now we are failing to feed the children. We are also finding it very difficult to keep or manage 100 children. Some of them have stopped coming to school." (CBO representative)

Some HBC givers reported that they had stopped visiting the homes of people living with HIV and AIDS as they no longer had food to bring to houses. District interviewees described an imbalance of service provision since CRAIDS ceased in Mumbwa, with more of a focus on treatment and prevention than care and support services.

Importance of continuing the HIV and AIDS community response

There was a perception among national level interviewees that most CBOs no longer existed since CRAIDS had ceased funding. While this may be the case in other districts, all CBOs that received funding in Mumbwa existed and were functioning in 2010.

Respondents reported the importance of the community response to HIV which was praised for being the "only way to fight the pandemic" through community determination and hard work. Care givers had closer links as they lived within the community, and in essence are the community.

"I think one of the strengths of the programme was that it gave people at the community level an opportunity to identify what the real issues affecting them were and at the same time it also provided people with the opportunity in finding a solution using their own methodologies of addressing whatever issues they had prioritised." (District level stakeholder)

ORGANISATIONAL CAPACITY BUILDING

All CBOs funded by CRAIDS reported capacity building activities – training for HBC, psycho- social counselling, adherence support and peer education. On the business side, capacity was built in management skills, treasury and banking issues and reporting. Training took place primarily in the form of workshops. CBO representatives reported also building one another's capacity by passing on skills from training initially received through CRAIDS. This promoted sustainability and boosted morale amongst volunteers.

However, respondents also reported that skills had been lost over time, as some of those who had received training had moved on to other activities or out of the districts. Others reported a loss of capacity over time, due to HIV medical knowledge and guidelines becoming outdated.

Volunteers – the pulse of the community response

Volunteers are at the heart of the care and support services provided by CBOs for people living with and affected by HIV and AIDS. They provide a wide range of services including psycho-social counselling, HBC, treatment adherence support, peer education and sensitisation. The numbers of volunteers in individual CBOs in Mumbwa ranged from 10 to 110. They would walk long distances to provide HBC to families living with HIV and AIDS and to bring reports to the DATF. Most CBOs reported a decrease in volunteer numbers since CRAIDS ceased. A decrease in the morale of volunteers was frequently lamented by interviewees, primarily due to a lack of materials to carry out their work, such as HBC kits, washing and cleaning materials. Some had resigned due to work overload.

Hammer Mill in use by a CBO in Mumbwa district

COORDINATION AND PLANNING

The District AIDS Coordination Advisor (DACA) is held in high regard by most organisations in Mumbwa and he has continued to advise, coordinate and monitor them since CRAIDS ceased. The importance of having a local leader with in-depth knowledge of the community was mentioned by many of the CBOs as being the key to the community response, who also praised the DATF for preventing duplication of services in Mumbwa. Recruitment of DACAs to implement the activities and responsibilities of the DATFs is a priority for NAC in its new strategic framework, 2011-2015. Community AIDS Task Forces (CATFs) operated in the same way as the DATF but at the community level – they monitored services, organised World AIDS Day events, and mapped services. CATFs did not receive funding from CRAIDS.

Cooperation with other organisations

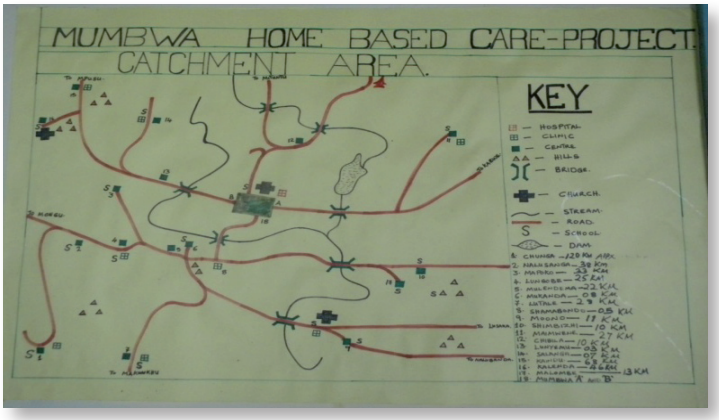
Many CBOs described positive working relationships with other CBOs, NGOs, hospitals and clinics in Mumbwa. This relationship ranged from reciprocal arrangements – referring and bringing sick people to hospital for treatment, and the hospital or clinic referring patients to CBOs for HBC. It was reported that PEPFAR funded organisations had begun to align with government at the national and district levels. A number of CBOs did not cooperate with other CBOs and displayed no knowledge of other organisations operating in their catchment area. Others cooperated in the organisation of World AIDS Day events only.

Example: CBO for Home Based Care:

The relationship between the CBO and the hospital has changed over the last ten years, due to improved coordination at the district and facility levels. The CBO can now approach hospital staff with questions relating to the medical conditions of the people they serve, and there is an established link between community-based counsellors and ARV programmes. Some of the CBO caregivers have been given positions on hospital committees and the hospital has lists of all the care givers who work in the area. Counsellors from the CBO reported working in the clinic as a team alongside medical staff.

Monitoring and Evaluation

National Activity Reporting Forms (NARF), which are used to report to NAC, and MoH reporting systems exist in parallel. NARFs report on aspects of HIV and AIDS care and support at the community level. In 2010, some CBOs and CATFs stated that reporting had become a bigger challenge due to the DACA no longer having the resources to buy fuel to travel to CBOs to collect reports. As a result, some CBOs stated that they no longer reported up to the districts and only reported down to their communities. It was reported that CBOs and communities were more motivated when they were being monitored. There was a perception that the numbers of CBOs that had registered with the DATF had increased since 2008. Situation analyses of community based care and support services began in 2011 in a number of districts in Zambia. However, they were not being undertaken uniformly nor in all districts.



Map of Mumbwa Home-Based Care Project catchment area

Future models of funding of HIV care and support services

National level interviewees highlighted potential mechanisms for future funding of HIV and AIDS care and support services. A key issue was whether the DATF would continue to sit under the District Commissioner or the District Council. Some interviewees reported a preference for the latter option, working through the district planner and the district investment plan, as it was argued that this would allow care for people living with HIV and AIDS to be further integrated into the mainstream district planning processes.

Respondents reported that the legal instruments are not yet in place for decentralisation and the DATFs and are not currently located within the decentralisation plan. One potential future funding mechanism mentioned by a national level stakeholder was the introduction of a Joint Financing Agreement for CBOs where Cooperating Partners would put funds into a joint pot at the national level, which could be managed through establishing an independent financing organisation.

RECOMMENDATIONS FROM COMMUNITY LEVEL FINDINGS

1. **Conduct a comprehensive situation analysis of community-based HIV and AIDS care and support services and needs** within each district, country-wide. This should inform evidence-based planning for a community-based AIDS prevention, care and support response. Specifically the analysis should include the following:

• *Systematically map the HIV and AIDS care and support services that organisations currently provide in each community within each district.* Services to be mapped include: HBC visits, food supports/supplements, support OVCs, HIV Counselling, treatment adherence and IGAs. Data already collected from NARFs can provide a starting point. However, it will not be sufficient to count services and client numbers; services currently being delivered also need to be mapped by catchment areas to provide clear maps of service distribution.

• *Needs assessments* for each of the above services should include: estimates of the numbers of PLWHAs and their families and OVCs in need of these services in community catchment areas and numbers receiving these services. This information can be used to estimate current coverage levels and coverage gaps for each service in each catchment area. Funding for care and support should be based on valid and reliable estimates of service need and coverage gaps.

• *Existing funding sources:* DATFs to systematically map all current funders of HIV and AIDS services within the district.

• *CBOs' capacity:* Assessments of CBO capacities need to be conducted across each district to harness the experience of CBOs/NGOs that are working in this area, who can help to develop the capacities of other organisations. This could be undertaken under the coordination of the DATFs.

• *Map existing links between CBOs and health facilities (clinics and hospitals):* as with care and support services, existing linkages - for supporting treatment adherence, counselling and HBC follow up- could be formalised and strengthened as part of any new programme of support to DATFs, and coverage gaps can be targeted for developing new support linkages.

2. **Maximise use of existing funding sources:** Where funds to support HIV and AIDS care and support activities at the district and community levels are currently available:

• The existence of funding sources and mechanisms for accessing them need to be communicated much more effectively to CBOs.

• Funders need to make their funding conditions more explicit to CBOs and other potential recipients.

• Both of these recommendations could be implemented by working through the DATF and CATF, learning from the CRAIDS experiences; and using media such as newspapers and local radio more effectively.

OPTIONS FOR FUNDING AND SUPPORTING COMMUNITY AIDS CARE AND SUPPORT SERVICES

Study findings, especially the national level interviews, highlighted two mechanisms for providing future funding and support from the national level to AIDS, care and support activities at the community level:

1. **Mainstream HIV care and support services within broader poverty alleviation funding channels,** such as existing schemes within the Ministry for Community Development and Social Services, Ministry of Education and the Ministry of Health. This approach would need to establish accessible mechanisms and ensure that:

   a. The needs of communities, families and people living with HIV and AIDS are prioritised and that they receive the specialised support services they need.

   b. CBOs that provide these services can directly access funds to provide them, and receive the capacity supports to ensure service quality.

   c. Continued existence and support to community and district coordinating bodies (CATFs and DATFs), given the potential for duplication and coverage gaps.

2. **Retain a separate funding stream for community AIDS care and support activities,** as a continuation of - or building on the best features and lessons learned from - the CRAIDS model.

   a. Poverty alleviation and support activities for those affected by and living with HIV and AIDS could be undertaken through a poverty alleviation channel, while

   b. More specialised AIDS care and support activities (counselling, treatment adherence, HBC and others) could be supported through an AIDS support channel.

The findings of his study have highlighted the importance of retaining and supporting a specific community response, rather than relying only on a generic poverty alleviation approach to meeting the needs of people living with HIV and AIDS. These people will continue to need to access to home-based care, treatment adherence support, counselling services, transport to health centres and nutritional support. While poverty is both a determinant and a frequent outcome of HIV and AIDS, which needs to be directly targeted, these are essential care and support services that are vital to ensuring an effective and comprehensive response to the epidemic.

References

Birdsall K, Kelly K: **Pioneers, Partners, Providers: The Dynamics of Civil Society and AIDS Funding in Southern Africa.** Centre for AIDS Development Research and Evaluation (CADRE): 2007

McIntyre K, Carey S: **Assessing the Contribution of Civil Society Organisations to the National Response on HIV and AIDS in Zambia, 2006-2008.** Lusaka, NAC Zambia: 2009

Ndubani P, Simbaya J, Walsh A, Kamwanga J, Brugha R: **Tracking Global HIV/AIDS Initiatives and their Impact on the Health System in Zambia. Final Report.** Global HIV/AIDS Initiatives Network: 2009

About the research:

The study was undertaken in 2010 and early 2011 by Chishimba Mulambia, a Zambian research consultant, who is a research fellow at the Institute of Economic and Social Research at the University of Zambia, working with the GHIN team at the Royal College of Surgeons in Ireland (Ruairí Brugha and Aisling Walsh) and Johanna Hanefeld, a research consultant who was based at the London School of Hygiene and Tropical Medicine. The study was funded by the Open Society Institute (OSI) and was conducted with support from Global HIV Initiatives Research Network (GHIN: www.ghinet.org), which is co-funded by Irish Aid and Danida. The authors would like to express sincere appreciation to the community based organisations who particiated in the study, and also to the district and national level respondents for their participation. A special thanks goes to Mumbwa District AIDS Coordinaton Advisor.