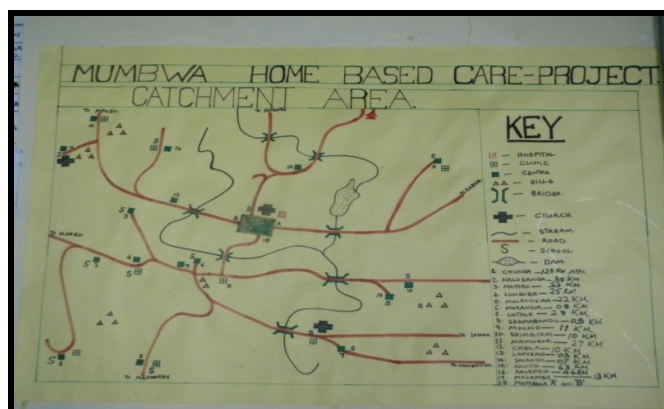


The evolution and sustainability of Community Based Organisations providing HIV and AIDS care and support services in Zambia – lessons from Mumbwa district

Study findings and recommendations



Global HIV/AIDS Initiatives Network (GHIN)

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1. STUDY BACKGROUND

1.1 INTRODUCTION

The decade 2000-2010 saw a massive global scale-up of HIV and AIDS services resulting in large numbers of people accessing prevention, treatment, care and support programmes, especially in sub-Saharan Africa. The Zambia Demographic and Health Survey (ZDHS) 2007 (CSO, 2007) reported that 14.3% of Zambian adults aged 15-49 years were HIV positive, suggesting a slight decline in infection levels from an earlier (ZDHS, 2002) 16% estimate.

Community Based Organisations (CBOs) are a form of Civil Society Organisation (CSO), which are rooted in and emerge from communities. CBOs have been providing important advocacy, care and support services for people living with HIV and AIDS in Zambia since its emergence in the mid to late 1980s. They also work with health facilities, hospitals and other district level organisations that provide core HIV and AIDS services. After the 1991 election in Zambia – and the introduction of the multi-party system – the number of CSOs, especially Non Governmental Organisations (NGOs), began to mushroom. Most of these newly formed organisations were dependent on donor funds from the outset (Scanteam, 2007).¹

CSOs can be divided into those that provide ‘hard’ services (usually NGOs), which in the area of HIV include preventive and therapeutic commodities, and those who provide ‘soft’ services (often CBOs) such as care and support to people living with HIV and AIDS. Birdsall and Kelly have estimated that the number of CSOs working in the HIV and AIDS sector has increased tenfold since the 1990s (Birdsall and Kelly, 2007). A recent study commissioned by the National AIDS Council (NAC) found that between 2006 and 2008, CSOs provided around 30% of VCT services, 80% of treatment, care and support services; and 70% of support services to orphans and vulnerable children (OVCs) (Macintyre and Carey, 2009). Over 75% of CSOs working on HIV and AIDS are CBOs or local NGOs, 20% are international NGOs and over 22% have a religious affiliation (Birdsall and Kelly, 2007).

¹ Here we categorise CBOs as bottom-up forms of CSO that have emerged from the community, usually deliver home-base ‘soft’ services such as home visits, care and support for people living with AIDS. They are often informal and lack the developed structures of NGOs, which are a more formal form of CSO that sometimes lack the strong community roots of CBOs.

1.2 THE WORLD BANK MAP

Launched in 2000, the World Bank Multi-County AIDS Program in Africa (MAP) was the first Global Health Initiative (GHI) that was established to fight HIV and AIDS and it laid the foundations for the massive scale-up in external funding for the disease during the following decade (Ndubani et al, 2009). It was specifically aimed to provide long-term support (10-15 years) to combat HIV/AIDS and mitigate its impact in African countries. Designed to be demand-driven, multi-sectoral and community oriented, the Africa MAP was different from traditional World Bank lending, although projects were intended to fit within the country's development strategy and the Bank's strategy for overall lending in that country.

Three pre-conditions were established to qualify for MAP funding. Countries must: 1) produce a national strategic plan 2) establish a national coordination body and 3) make a commitment to disbursing 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. The project characterised itself as a financing mechanism for high priority interventions for which significant funding gaps existed.

The objective of the ZANARA project was to prevent and reduce the spread of the HIV and AIDS epidemic, mitigate the socio-economic impact of the disease, and increase access to care and support for the people infected or affected by the epidemic in Zambia. In order to successfully meet its objective, ZANARA provided support through four components namely: (i) the Community Response to AIDS (CRAIDS); (ii) NAC and its Secretariat; (iii) line ministries and (iv) a Programme Administration Unit (PAU) at the Ministry of Finance and National Planning.

Funds were disbursed by ZANARA to all the line ministries and yearly activity plans were drafted jointly by individual ministries. ZANARA/CRAIDS funding was provided as project rather than budget-support. CRAIDS was created to fill a gap by providing resources for community based programmes and accounted for 35% of total MAP commitments in Zambia (World Bank, 2009). Although the initial target was to fund 350 projects, CRAIDS funded 1,800 community initiatives (World Bank, 2009). The UK Department for International Development (DFID) provided additional funding for CBOs through the Strengthening the AIDS Response Zambia (STARZ) project, from 2004 to 2009 (Siamwiza, 2007).

Key CRAIDS activities included support for:

- community based initiatives
- the district HIV and AIDS response through capacity building activities
- NGOs with programmes that address the needs of communities

- the private sector to support workplace programmes.

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 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). By 2006, 62% of external funding to HIV/AIDS control in Zambia was provided by PEPFAR and 13% by the Global Fund (Oomman et al, 2007, Global Fund, 2009).

Whilst some stakeholders in Zambia were expecting the World Bank *Agenda for Action 2007-2011* to result in a continuation of MAP (Hanefeld et al, unpublished), the policy actually resulted in a complete change of agenda. The World Bank offered a loan of US \$20 million to the Zambian Government in 2008 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, having extended its closing date from the end of February 2008 to complete CRAIDS implementation.

1.3 STUDY OBJECTIVES AND RATIONALE

The aim of this 2010-11 study, findings of which are presented here, 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 Community Based Organisations (CBOs) working in this field at the community level in one district of Zambia. Specific 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

The rationale for these objectives was that early reports had suggested that some MAP funded CBOs were left with no funds and the continuation and sustainability of their services were in doubt (Hanefeld et al, unpublished). Earlier studies and evaluations, at or shortly after the MAP had ended, had focused on:

- a) predicting what would occur with the closure of MAP (Siamwiza, 2007);
- b) the wind down period and immediate aftermath in 2008-09 (Hanefeld et al, unpublished); and

c) World Bank internal completion and results report (World Bank, 2009).

This study aimed to produce evidence on what was the current status and activities of these CBOs, two years following the cessation of MAP/CRAIDS, when deeper effects were likely to have emerged. Questions to explore through interviews with CBO representatives were:

- what were the range and scale of their HIV and AIDS advocacy and support service activities at the district and community level; and
- how had these been affected by the cessation of World Bank funds.

The World Bank *'Implementation Completion and Results Report'* (2009) had suggested that a case study on CRAIDS could shed more light on the enabling factors for community initiatives and suggested issues that should be explored, including: involvement of community members in CBOs and CBO activities; the effectiveness of accountability mechanisms in project management; and the use of reliable M&E systems.

The purpose of this 2010/11 study has been to:

- (A) provide evidence to policy makers at the national level, including Government (NAC, MoH and Community Development) and to development agencies (World Bank, bilateral donors and others working in HIV and AIDS), to enable them to plan for future support to CBOs and the HIV and AIDS care and support activities that they are uniquely well-placed to deliver; and
- (B) provide a voice to district/community level stakeholders, especially CBOs and their representatives, on the activities and needs of (previously CRAIDS funded) CBOs in Zambia and to allow them articulate how future support to these organisations should be delivered.

The study was undertaken in 2010, with follow-up national level interviews in early 2011. Ethical approval was granted by the University of Zambia Research Ethics Committee.

The study was funded by the Open Society Institute (OSI) and was conducted with support from the Global HIV Initiatives Research Network (GHIN: www.ghinet.org), which is co-funded by Irish Aid and Danida.

1.4 METHODS

Mumbwa rural district was selected as a district where CRAIDS funded many CBOs and where the District AIDS Task Force (DATF) remained active, despite CRAIDS cessation. There were other funders of HIV and AIDS control activities present in Mumbwa district during the period of interest, 2007-10. Selecting one district allowed for a more in-depth exploratory study of the issues than would have been possible with structured surveys across several districts. The limitation is that the findings may not be fully representative of the post-

CRAIDS experiences of HIV and AIDS support CBOs in Zambia. National stakeholders working in the field, especially NAC, are best placed to make this judgement.

All CBOs in Mumbwa district that had received CRAIDS funding were identified with the support of the DACA and representatives from all of these were interviewed (n = 18). District level interviewees included representatives of the District AIDS Task Force (DATF), 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). Interviews were recorded (with the permission of the respondents), transcribed and a thematic analysis was conducted, on which these findings are based.

A draft of the report summary and recommendations was tabled at a dissemination meeting in Lusaka on 2 March 2011. The event was chaired by the Director General of the National AIDS Council, Dr Ben Chirwa. Senior representatives of the relevant Ministries (Education, Health and Social Protection) and most of the major donors and development agencies – Irish Aid, DfID, USAID, EU, JICA, World Bank and UNDP – attended and discussed the findings.

2. FINDINGS

2.1 FUNDING

2.1.1 Funding pre-CRAIDS

All eighteen CBOs in Mumbwa that received CRAIDS funding between 2004 and 2008 had existed prior to receiving CRAIDS grants, some as early as 1992. This is contrary to the perception from some national level respondents that CBOs emerged and were established in order to access CRAIDS funds, without proper plans in place to serve the community of people and families living with HIV and AIDS. CBO respondents reported that these organisations were formed due to an increase of HIV and AIDS in their community and in particular the rise of orphans and vulnerable children (OVCs). Many of these were initiated as women's clubs. Of the CBOs that received CRAIDS funding, nine 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.

Funders of CBOs in Mumbwa prior to CRAIDS included the Programme Against Malnutrition Zambia (PAM); Heifer International; the Churches Health Association of Zambia (CHAZ); Millennium Challenge Corporation (MCC); the NGO Coordinating Council for Gender and Development (NGOCC) Zambia; and the Government's Constituency Development Fund (CDF), which funded small grants and income generation activities. Whilst CDF is still active, it was reported by the CBOs that the others were no longer funding services in Mumbwa in 2010.

2.1.2 The CRAIDS era

2.1.2.1 The CRAIDS process

Most CBOs heard about CRAIDS funding through the District AIDS Coordinator (DACA) and the CRAIDS regional facilitator. The process for assessing proposals submitted by CBOs was as follows:

1. The CBO submitted a proposal to the DATF, usually through the DACA.
2. The DATF assessed the quality of the proposal and passed it to the District Commissioner to be reviewed.
3. Field appraisal ensued, to ensure complementarity and no duplication with other activities / proposals.
4. The District Commissioner then approved and signed off on grants for proposals that had been recommended for funding.

5. Quotations for the purchase of materials or commodities needed for carrying out care and support activities were then sourced by the CBO and approved by the DACA.

Most CBOs that had been approved for funding received the promised funds between 2005 and 2007. However, some CBOs reported that there had been delays in the receipt of CRAIDS funds – one organisation applied in 2002 and only received funding in 2006; another applied in 2004 and was funded in 2007. Some CBOs received a lump sum while others received their funds in instalments. The size of grants per organisation ranged from K38 million (approximately US \$ 8000) to K72 million (approximately US \$15000), which they received in payment vouchers or cheques.

Although the initial target was to fund 350 projects, CRAIDS funded 1,800 community initiatives. 5,000 funding applications were received and receipt of proposals was suspended by mid way through the project as by that time all planned resources had been committed (World Bank, 2009).

2.1.2.2 The community view of how they received CRAIDS funding

In general CRAIDS funding was viewed positively by most of the CBOs in Mumbwa who were interviewed. CRAIDS 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 CSOs (CBOs and NGOs) register and open a bank account (see section 2.2 and 2.3 for views of effects of CRAIDS funding).

However, conditions specified which services were to be provided. Many of the CBOs were unhappy with these conditions and not all received funding for the services for which they applied. For example, one CBO applied for cattle, but was given funding to engage in poultry farming. Another applied for home-based care but was funded to undertake awareness campaigns, as it was told that there were too many CBOs doing HBC in the area. Another applied for Income Generating Activities (IGAs) generally, but was given money for sensitisation and to purchase food. Many thought that they should have allowed more funds to go into sustainable plans.

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. One of the primary conditions was that CRAIDS funding could not be used to provide allowances to volunteers for providing services.

2.1.3 CRAIDS cessation

In 2007, a report commissioned by the National HIV/AIDS/STI/TB Council (NAC) recommended to the World Bank and Government to plan an exit strategy for ZANARA/CRAIDS; and recommended that CRAIDS be re-

named and moved to NAC to be a specialised unit that would serve as the link between government and civil society (Siamwiza, 2007). At the end of 2006, only 27% of the 5000 projects had reached the Central Management Unit screening stage and only 24% had been approved (Siamwiza, 2007).

Community respondents in this study reported that the DACA informed many CBOs that CRAIDS funding was coming to an end, although he himself had received no formal notification of this. According to district and national respondents, the CRAIDS regional coordinator was transferred and the office was closed without formal communication to district level stakeholders. This resulted in the DATF no longer having control over which CBOs were receiving money, despite remaining in a coordinating role for service provision in Mumbwa. It was reported by some district and national respondents that this weakened the position of the DATF as a coordinating and planning body, as had also been reported in the earlier GHIN study (Ndubani et al. 2009).

Most CBOs were clear from the outset about the total amount that they were being awarded and the duration of their grants; and many received a certificate of grant completion. 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 plans in place.

2.1.4 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.

Funders known to CBOs in 2010 but reported as not currently funding CBOs in Mumbwa included: Family Health Trust, Forum for African Women Educationalists of Zambia (FAWEZA), *Changes Zambia* and District Business Association (DBA). While it was believed that the CDF still existed, it was not easily accessible as only a small amount of money was divided across the entire CBO constituency. It was thought that most of the CDF funds were allocated to fixing existing infrastructure. It was also perceived that, while CHAZ had funded four CBOs in Mumbwa in the past, they were 'on a break' in 2010.

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 PEPFAR amongst CBOs in Mumbwa, or of the different grants that PEPFAR currently provided which CBOs would be eligible to apply for. PEPFAR grants include those that support i) OVCs ii) prevention activities and iii) community compact programmes designed to give more power to the community.

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 throughout the country. One national level respondent put this forward as an alternative to funding CBOs, whereas others outlined the importance of maintaining support for the community in addition to the cash transfer scheme.

2.2 CBO SERVICE PROVISION

2.2.1 Services provided by CBOs

CBO representatives gave details of the services they provided, which were centred on care and support services – specifically HBC, nutrition support, general OVC support, peer education and HIV counselling. Prevention services focus primarily on sensitisation. CBOs are the most active providers of these services 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.

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.

2.2.2 Effectiveness and sustainability of Income Generating Activities

CRAIDS funding has provided some CBOs in Mumbwa with 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. Infrastructure— primarily markets and roads to support IGAs— do not exist in many areas of Mumbwa. 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. The lack of plans to encourage broader community development and address *“factors that encourage growth within social settings”* resulted in money being pumped in without achieving sustainable community support activities.

It was reported that too many similar IGAs exist in a small geographical area, creating too much competition amongst organisations. If a community saw a CBO was making money on a hammer mill, then they also sought to do the same without looking at whether the market was in place for this to occur.

“Each time a community decided on an IGA, then it was making returns, then competition came in from new comers. The outsiders wanted to do also exactly the same thing. So they lost on the market.” (District stakeholder)

In other cases, IGAs such as a diesel-powered hammer mill were undercut by more competitive alternatives, such as electricity-powered mills, which rendered the former economically unviable.

“With the hammer mill the income is very slow because we are in the midst of people who have electric hammer mills that are even more efficient, for us it’s a diesel hammer mill and the diesel consumption is very high so we charge K2000 per grinding and those with electric hammer mills charge K1000 so that difference kills our business.” (CBO representative)

It would appear that individual CBOs were not well placed to identify IGAs with a good chance of longer term success and may have lacked the capacity and technical advice and support to translate good ideas into sustainable IGA programmes.

Some CBOs complained that they a) unsuccessfully applied for IGAs or b) were not permitted to spend enough on these activities. However, there were also positive reports of successful IGAs. Purchase of a hammer mill through CRAIDS support enabled one CBO to open a grocery shop. Also, even if some IGAs were not sustainable, such as vegetable farming, they did enable CBOs to produce food to support people living with HIV and AIDS through HBC programmes.

2.2.3 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 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 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. We are struggling to keep the school going and to retain the number of pupils attending class.” (CBO representative)

Some HBC givers reported that they had stopped visiting the homes of people living with AIDS as they no longer had food to bring to houses. Examples of reductions in services included: a reduction of OVC support from 100 to 70 orphans and from 300 to 110 care givers. One CBO reported having 700 people on the list but with grants for only 50. Out of ten organisations providing HBC, only one reported that their service levels had remained unchanged since they stopped receiving CRAIDS funding.

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. Some perceived that the priority within Mumbwa district in 2010 was to ensure people receive ARVs with little or no emphasis on nutrition and support to the community as a whole, nor to the families affected by HIV. CBOs described the difficult decisions they were forced to take around which OVCs to support, and which to neglect. One organisation chose double orphaned children, i.e. those who had lost both parents to AIDS. Another chose the first 50 children on their list, neglecting those who had been identified more recently.

National level respondents in late 2010 spoke of other funding schemes, which might or could fill the gap left by CRAIDS. For example, the Ministry for Community Development and Social Services (MCDSS) takes

guidance from NAC on HIV and runs cross-cutting programmes such as a food security programme, and a women and development programme. The Ministry of Education (MoEd) runs a public welfare assistance scheme, which includes the provision of school fees and uniforms, and a school feeding programme. However, none of these schemes were mentioned by any of the CBO representatives we interviewed in Mumbwa.

2.2.4 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. One CATF spoke about promoting sustainability being at the core of its strategy. They instilled the ethos that external funding was additional, including support from the district.

“So we are very successful because we have not believed in living on sponsorship. We have believed that we must be self sustainable in our own small way because that’s the only way we can fully exist. Because if we normally depend on sponsorship or funding outside our community then we may not function and that’s the policy we have. We told most of the support groups these are just there to help, the problem is ours, it is not CRAIDS, it’s not for Family Trust and it’s not for the district.” (CATF representative)

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.” (National level stakeholder)

2.3 ORGANISATIONAL CAPACITY BUILDING

2.3.1 Capacity Building by CRAIDS

One of the major benefits of CRAIDS lay in its training of volunteers in service provision and business management, and limited training on IGAs. This increased the capacity of CBOs and enabled community empowerment. 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.

“The capacity that was built for me was how to do things in the bank. I had never seen how it looks inside the bank. I did not know what a cheque looked like and I never had the knowledge of why cheques are rejected. I even knew how to withdraw and bank the money.” (CBO representative)

CRAIDS was more broad-based than other organisations as it empowered the community through capacity building roles. 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. One such example was the change in WHO guidelines to start patients on ARVs at a CD4 count of 350 rather than 200. Others reported that they would have liked for the training to be more tailored to suit their specific needs. One respondent remarked that even if the capacity of some organisations was improved by 100%, they would not be able to handle the larger funders such as USAID.

2.3.2 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. Volunteers described their motivation as coming from a desire to improve their community through determination and hard work. Volunteers would walk long distances to provide HBC to families living with HIV and AIDS and to bring reports to the DATF. Some reported volunteering with the same organisation for up to ten years. Interviewees explained that people living with HIV and AIDS preferred to be counselled by voluntary groups in their community, which they saw as the big comparative advantage of CBOs.

Most CBOs reported a decrease in volunteer numbers since CRAIDS ceased. While a condition of CRAIDS funding was that it could not be used to provide allowances or incentives to volunteers, some received allowances from monies raised through IGAs, though they were not formally paid. 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.

2.4 COORDINATION AND PLANNING

2.4.1 District Coordination Structures

The DACA, with whom CBOs reported having a strong relationship, is held in high regard by most organisations in Mumbwa and he has continued to advise, coordinate and monitor them. Organisations mention that the need for the DACA is even greater now than when CRAIDS was in place. 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.

“Because DATFs are based locally, they did desk and field appraisals and were able to identify areas of weakness which went beyond the check lists of the tools for monitoring.” (National level respondent)

At the time of the community interviews in 2010, there was a question mark over whether the position of the DACA would continue to exist. Funding, which came from the United Nations Development Programme (UNDP), had reduced significantly and it was thought that the position might be phased out completely. A shortage of resources was cited as the reason, as the DACA frequently did not have enough fuel to visit CBOs that were far from Mumbwa town. Since the community and district interviews took place, it was reported that funding for DATF had been secured through a Global Fund grant, channelled through the NAC, and the structures appeared to be secure for at least the next two years. Recruitment of DACAs to implement the activities and responsibilities of the DATFs is a priority for NAC in its new HIV and AIDS Strategic Framework, 2011-2015. The fact that the office of the DACA is now physically located within the District Health Office was seen as a positive development, as it was now firmly situated within the government health system.

One stakeholder explained how the emphasis and onus should be placed more on the DATF rather than on promoting a ‘one-person show’ in person of the DACA. It was also suggested that the title could be specialist rather than advisor, to emphasise the operational rather than the advisory role of the post. Not all CBOs were aware of the CRAIDS Regional Coordinator, whose role was to give technical support to the PATF and DATF. When the Regional Coordinator did visit the district, s/he always accompanied the DACA and there was a general lack of understanding at the community level of how to distinguish the roles.

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 but in some cases received once off funds from the DACA for hosting meetings and World AIDS Days. While most communities had CATFs in place, some reported that it was not possible for them to cover the entire catchment area. The CATFs in Mumbwa district reported a positive relationship with the DACA and with the health clinics and hospitals.

2.4.2 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/bringing sick people to hospital for treatment, and the hospital or clinic referring patients to CBOs for home-based care. It was reported that PEPFAR funded organisations had begun to align with government at the national and district levels.

Example - CBO for Home-Based Care: The relationship between the hospital and the CBO has changed over the last ten years, due to improved coordination between districts, facilities and community 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.

Some CBOs described cooperating with area associations outside of HIV, such as Womens' Associations and World Vision Community Care Coalitions. While CRAIDS facilitated this in many instances, other avenues were sometimes used, such as Women's Associations and through their own initiatives and those of Nangoma hospital. 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.

2.4.3 Monitoring and Evaluation

National Activity Reporting Forms (NARFs), which are used to report to NAC and MoH reporting systems exist in parallel, and report on aspects of HIV and AIDS care and support at the community level. NARFs capture additional indicators specific to CBOs, such as Information Education Communication (IEC), OVCs and HBC. In 2010, some CBOs and CATFs stated that reporting had become a bigger challenge due to the DACA no longer having funds to purchase fuel to travel to CBOs to collect reports. As a result of this, some CBOs stated that they no longer reported up to the districts and only reported down to their communities.

Some respondents reported that this lack of reporting and monitoring had weakened the DATF and that CBOs and communities were more motivated when they were being monitored. CBO representatives referred to the importance of there being a local person (the DACA) to monitor them, as s/he had an in-depth knowledge of the needs of the community, which was not the case with someone from the national level.

“So there was close monitoring as a result of that because people were living in the same community rather than these organisations that operate on remote control where people are very far.” (CBO representative)

Many of the organisations interviewed for the study were not aware of the NGO Act (2009) and there was general uncertainty as to its implications. Those that were aware were generally positive about its introduction, suggesting that it would increase their visibility and make it easier for them to open a bank account. It would also help decrease duplication and waste of resources, as CBOs would be obliged to register with the DATF. There was a perception that the numbers of CBOs that had registered with the DATF had increased since 2008. CBOs would also soon be obliged to pay a registration fee to the Council.

At the time of writing this report, NAC was building capacity of local authorities to develop directories of community based organisations in a number of districts in Zambia. However, they were not been undertaken uniformly nor in all districts.

2.5 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 which arose 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.

Some national level stakeholders considered that NAC should not become a granting institution, but rather it should continue in its coordinating role at the national level, and through ensuring that HIV and AIDS remain on the development agenda. NAC has taken some positive steps in this regard, though the appointment of Provincial and District Multi-sectoral Response Specialists. However, respondents reported that the legal instruments are not yet in place for decentralisation and the DATFs and PATFs are not currently located within the decentralisation plan.

It was reported that NAC (though UNAIDS) were undertaking an expenditure tracking survey at the time of the interviews (late 2010) to track how resources for HIV and AIDS care and support services are being expended at the community level and looking at sub-granting mechanisms for community based services. One potential future funding mechanism mentioned 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.

3. RECOMMENDATIONS FROM COMMUNITY LEVEL FINDINGS

3.1 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 care and support response. Specifically the analysis should include the following:

- a. *Mapping HIV and AIDS care and support service provision:* Systematically map the HIV and AIDS care and support services that organisations currently provide in each community within each district.
 - i. *Organisations* include: (i) Government - to include health facilities and Local Government (ii) NGOs and (iii) CBOs.
 - ii. *Services* to be mapped include: home-based care visits, food supports/supplements, support to 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.
- b. *Needs assessments* for each of the above services should include:
 - i. estimates of the numbers of people living with HIV and AIDS and their families and OVCs *in need of* these services in community catchment areas (actual numbers can be supplemented by modelling of the numbers);
 - ii. numbers receiving these services. Together this information can be used to estimate
 - iii. 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.

- c. *Existing funding sources:* DATFs to systematically map all current funders of HIV and AIDS services within the district.
- d. *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. District-wide capacity-building plans need to be funded in a coordinated fashion.

- e. *Map existing links between CBOs and health facilities (clinics and hospitals):* as with care and support services (see a, above), 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. Where linkages do not exist, coverage gaps can be targeted for developing new support linkages.

DATFs could place a key role in conducting situation analyses (the service mapping and needs assessment). However, given the ambitiousness of conducting a national situation analysis of community AIDS care and support needs, a pragmatic approach would be to explore to what extent knowledge needs and questions could be incorporated into other / ongoing District Situation Analyses.

3.2 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:

- a. The existence of funding sources and mechanisms for accessing them need to be communicated much more effectively to CBOs.
- b. Funders need to make their funding conditions more explicit to CBOs and other potential recipients.
- c. Both of these recommendations could be implemented by: i) working through the DATF and CATF and also by learning from the CRAIDS experiences, and ii) using media such as newspapers and local radio more effectively.

4. 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:

❖ ***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 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.

❖ ***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.

- d. Poverty alleviation and support activities for those affected by and living with AIDS could be undertaken through a poverty alleviation channel, while
- e. More specialised AIDS care and support activities (counselling services, treatment adherence, HBC and others) could be supported through an AIDS support channel.

The findings of this 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, 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.

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