# BRADFORD CENTRE FOR INTERNATIONAL DEVELOPMENT



Community-driven development: understanding the interlinkages betw	'een
individuals, community-based workers and institutions.	

CDD Working Paper Series

# Working Paper No. 10

Case Study: Community-based workers and HIV/AIDS in Bloemfontein, South Africa

By Lindi Mdhluli with the African Institute for Community-Driven Development

August 2006

Community-driven development: understanding the interlinkages between individuals, community-based workers and institutions.

The purpose of this research is to identify the potential and constraints of community-driven management and service delivery by tracking the evolution of participation, in selected projects as shaped by the interface between individuals, community workers and institutions.

Pro-poor community-driven development is both enabled and constrained by individual identities, the actions of community workers and the workings of institutions. The positive aspects can be enhanced through a greater understanding of individual motivations, institutional processes and improved monitoring techniques. However, the limitations of such models must also be recognised.

This research has three objectives: (1) to understand individual participation in collective action; (2) to understand the contribution of community-workers to participatory processes; and (3) to understand the possibilities of 'getting institutions right' for propoor development.

The research analyses case studies of community-driven development activity in relation to water and HIV/AIDS in Tanzania and South Africa.

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This Working Paper Series is dedicated to the memory of

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# Working Paper 10

# Case Study: Community-based workers and HIV/AIDS in Bloemfontein, South Africa

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# **Key Findings**

- Among the young and unemployed members poor urban communities there is sufficient
  interest in participating in health care provision for the chronically ill. There selfmotivation and resulting participation often lasts until better paid employment is found.
- A focus on TB treatment can enhance access to the chronically ill, and circumvent HIV stigma. This TB focus is also secures evident results of CBWs work, which gives them institutional legitimacy and personal satisfaction.
- Hierarchy between CBW and professional nurses often lead to feelings of being depreciated among CBWs. At the same time, CBWs position as non-professional community volunteers is often not clear among the beneficiaries, who perceive the CBWs as extensions of the state.
- Improved institutional support in the areas of feed back & supervision, recognition, and remuneration would strengthen CBWs position and thereby improve sustainability and reach.

# Summary of CBW system Golan Batcha, Bloemfontein, South Africa

Institutional	Facilitating	Selection	Accountability	Incentives/motivation	Mechanisms	Tasks	Reach
Origins	Agent	Criteria			of in/exclusion		
Golan Batcha 1998, young people's initiative to volunteer in clinic was taken up by prof nurse, Sr Reid from municipality and turned into Golan Batcha CBWs	Municipality; Clinic; TB DOT programme	Initially none, people just volunteered to join up. Later: Knowledge of basic HBC preferred.	Clinic group leader; TB clinic nurse; head of health directorate municipality.	Training; status capital; irregular stipend R500 p/m; possible career opportunities; interesting job while being unemployed	Constitution says they can't take more members, now +- 28 and reducing. This is because of the lack of further training & guidance possibilities.	TB DOT support; health talks in clinic; HIV/AIDS pre-post counselling; HBC (basic hygiene; wound cleaning; first aid; case assessment)	28 CBWs; 10 talks p/m for 50; 1 CBW to 3 counselling patients (officially); TB patients & HIV patients most common

#### 1. Introduction

Community-based care has been promoted as the best option to curb the impact of HIV/AIDS. However it is dangerous to assume that communities have limitless resilience and capacity to care for dying people and provide for those they leave behind. There is an acute need for social protection and interventions to support the most vulnerable members of the community and households affected by this epidemic. The purpose of this research was to identify the potential and constraints of the community-based worker (CBW) system and service delivery, by tracking the evolution of participation in selected projects as shaped by the interface between individuals, CBWs and institutions. The key research question is: What are the possibilities and constraints of CBW systems in delivering pro-poor home-based care in the HIV/AIDS sector?

The case studied to examine this question in the South African context is a group of 21<sup>1</sup> community members residing in Mangaung Local Municipality, who call themselves Golang Batcha. Golang Batcha renders a comprehensive health service in seven primary health care clinics within the Mangaung area. For the purposes of this report we concentrated mainly on two clinics covered by the Golang Batcha CBWs, namely Batho clinic in Mangaung's ward 1 and Freedom Square in ward 11. These two clinics have unique characteristics, in terms of both constraints and potential, affecting community-driven development in the health sector.

The data presented here are based on action research methods such as diary writing, wealth ranking and recording techniques among community-based workers, on active participation of the researcher in daily activities of the CBWs, and on extensive interviews and follow-up interviews with CBWs and with institutional representatives.

<sup>&</sup>lt;sup>1</sup> There were 37 CBWs when we started the CBW project process in January 2004. Some have died of HIV/AIDS and others have been absorbed in a government programme called Community Development Workers.

# 2. Background to the communities

## 2.1 Socio-economic background

Mangaung Local Municipality is situated in the city centre of Bloemfontein, the capital of the Free State province and the judicial capital of South Africa. According to the new demarcation processes the municipal area stretches to include two major centres of apartheid's 'displaced urbanisation' (Botshabelo and Thaba Nchu). According to the 2001 Census, Mangaung had a population of 645,438, the second smallest population of the nine South African Cities Network, but with the largest municipal area. Because of its historical form of settlement the municipality has extremes of wealth and poverty. Between 1946 and 1996 the city had the fastest annual growth rate amongst South African cities at 4%. However this growth slowed dramatically in 1996-2001 and over ten thousand jobs were lost in the last decade (South African Cities Network 2005). The economy is based mainly on the social/community/government sector. Community services constitute 35% of economic output, followed by the finance sector (18%), trade (16%), transport (13%) and manufacturing (8%). The strength of Mangaung's economy lies in its role as a regional service centre, implying development potential in the trade, transport and service sectors. Its' weakness lies in a concentrated economy with high levels of unemployment, illiteracy and poverty.

Mangaung's economy constitutes about a quarter of the entire Free State economy. Sectors showing growth are transport and finance, while the construction and manufacturing sectors are experiencing negative growth. The Mangaung Economic Development Strategy (EDS) represents the official development policy with specific emphasis on economic development in the municipality. The ultimate goal of the EDS is to improve standards of living of the local community by identifying opportunities aimed at addressing job creation and economic growth. Statistics South Africa (2005) indicated that in September 2004 the unemployment rate was 26.2% with 4.1m unemployed people based on the official definition. Black women continue to be most affected by unemployment, with an unemployment rate more than seven times higher than white males.

#### 2.2 Profile of wards 1 and 11

The CBWs studied provide their services in ward 1 and 11 of Manguang, two areas described below.

#### 2.2.1 Ward 1

Ward 1 of Mangaung is an area with the highest building density in the Free State. The area consists of Cape Stands, Lusaka, Matlhomola, Tambo, New Clare, Shuping, 4 & 6, Mapikela and CODESA 1 (Hostel No.1). The main form of housing in this ward is formal brick houses since most people are benefiting from government-subsidised housing. There are still some old mud houses and a small number of shacks, especially in the newly formed informal settlements. The presence of the Central Business District (CBD) in close proximity to the residential area places the ward at the heart of Mangaung local municipality. In 1996 there were 10,849 people in 2,919 households living in the ward, with an average household size of 3.7.

Community profiling indicated that large parts of the population have difficult living conditions. Vulnerable groups in the community include the homeless, the aged, street children, orphans, single mothers and the unemployed. Most of the adult population is unemployed and the main source of household income is from social grants - either from the child support grant of R190 or an old age pension of R820 or both in some instances.

There are a large number of young people without opportunities to further their studies due to inability to access bursaries or study loans. There are high levels of crime, exacerbated by poverty and unemployment. The most prevalent crimes are theft and rape. Most rape cases go unreported but women and child abuse seems to be high (Khanya-aicdd 2005a). This is even more so in Tambo Square and surrounding informal settlements where there are high levels of poverty and alcohol abuse. In recent years there has been an increase in a number of shootings in the area. Ward 1 is perceived to be the most notorious ward especially with regards to crime.

The ward includes some of the oldest black settlements in Bloemfontein and in recent years these areas have expanded and become more urbanised. The same has been happening to the CBD as well as some formerly whites-only settlements further north. This transformation has seen the movement of businesses further north leaving a vacuum in the former core CBD. This has had a negative effect on Ward 1 with lack of infrastructure for new residents and many deserted buildings, some of which belong to the municipality. Urban planning has been unable to meet the

challenges of these changes. The quality of houses is bad and in need of immediate attention and lack of access to adequate housing remains an issue.

There are several common ailments amongst the communities in the ward including epilepsy, asthma, pneumonia, diabetes, tuberculosis (TB), stroke, hypertension and HIV/AIDS. Some of the cases are reported and monitored by the local clinic. Stigma highly influences people's attendance to clinics, especially with regard to HIV/AIDS.

#### 2.2.2 Ward 11

Ward 11 of Mangaung consists of Turflaagte Phase I & II and Freedom Square. The history of ward 11 dates back to the late 1980s when people erected informal dwellings due to backlogs in the former townships. Some of the people came from the neighbouring rural towns of Dewetsdorp and Wepener. Some basic services such as schools and health and recreational facilities are still lacking. The population of this area is estimated at 10,850 people with an average household of 3.6 people and an average annual income of R10,957. There is a high level of unemployment. Moreover, 43% of the labour force is in elementary occupation.

Fifty seven percent of households have access to electricity and just 36% have water supply either to their house or yard. According to the 1996 Census, 32% of households had flush toilets. Between 1995 and 1999 a range of development interventions took place, including the installation of electricity and solar phones, the construction of a primary school and Reconstruction and Development Plan (RDP) housing and tarring of a road. In 2001 a ward committee was elected and ward plans and an Integrated Development Plan (IDP)<sup>2</sup> were drawn up (Khanya-aicdd 2005).

There are high levels of illiteracy amongst the adult population. Many lack the skills required by the mainstream labour market. Most of the people are engaged in unskilled labour. Women are mainly engaged in sewing and domestic work in white suburbs. There are people who are keen to start businesses but there are no enough sites to set up business premises. This is coupled with a weak customer base because most people are unemployed and household income is very low and

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<sup>&</sup>lt;sup>2</sup> IDPs are statutory development plans that municipalities must design every five years. These form the basis for development resources from central government.

this limits consumption. As it is most people cannot afford to pay school fees or municipal rates for services. Most people live in shacks with just the bare basics. Many are still waiting for government RDP houses. This is a fairly new residential area and is growing rapidly.

Currently there is only one clinic catering for the growing number of people. Health is poor as the clinic is not able to cater for the needs of all the members of the community and other health centres are more than 5 km away. For people with access to the clinic the recovery rate is very slow as many live in abject poverty with no guarantees of food every day. The major reported diseases include hypertension, TB, pneumonia, malnutrition, and HIV/AIDS. Most of these diseases can be cured or at least treated to a manageable level. Stigma around HIV/AIDS and lack of co-operation between traditional healers and clinical medical practitioners are amongst the reasons why people fail to recover quickly. Other issues are that many people are not legally registered with the Home Affairs Office, ie they do not have South African identity document that would allow them to gain access to the clinic or other services.

# 3. Golang Batcha Community-based Workers (CBWs)

#### 3.1 Golang Batcha

Golang Batcha is a group of 21 community members residing in Mangaung Local Municipality. Golang Batcha was established in 1998 by ten young people who had just completed high school and had no employment opportunities. The group approached the head of nursing at the local clinic, Mmabana based in Rocklands. Their main focus was to address the deficiency of health care services in the fight against HIV/AIDS and other related diseases such as Sexually Transmitted Infections (STIs) and TB. Once the group was established they found that other young people also showed an interest in replicating what the initial members had started in their own local clinics.

Golang Batcha renders a comprehensive health service in seven primary health care clinics within the Bloemfontein area. The services offered by the organisation are not only confined to HIV-positive people, because they do not want to single out people based on their HIV status. The CBWs' aim was not to take over from the health professionals but to bring alive the concept of community development, as they wanted to work directly with the community at their homes. The CBW network is legally established and is supported by the Free State Health Department

and the Mangaung Local Municipality. The CBWs provide support to professional nurses through a range of activities including basic health education to clients, visiting clinics and health education institution, and outreach work to the communities served by a particular clinic. The CBWs also assist in doing follow up on members of the community who are not able to attend clinics as well as providing home-based care for patients identified by professional nurses.

The reception from different clinics was not the same; some health professionals felt that the CBWs were not capacitated enough to work for their clinics, and made the CBWs work in the gardens and clean the yard. Although this did not discourage the CBWs, whose main intention was to work on issues relating to the fight against HIV/AIDS, they felt that their energies are not being put to good use. For a year they were working in the gardens and sometimes being asked to help with filing in the clinic or staffing the front desk, depending on how busy the employed clinic staff were. Later CBWs were taken on a course to do home-based care and counselling. At the end of 2000 there were about seventy CBWs working from the seven clinics doing home-based care, counselling for HIV/AIDS patients in the clinics and identifying families that needed the assistance of a social worker.

The then head of the Mangaung Local Municipality Health Directorate, Sister Marianne Reid, gave overall support to the CBWs at that time<sup>3</sup>. Sister Marianne played a vital role in ensuring that the CBWs received training and eventually got stipends. She also helped in drawing up detailed reporting formats for CBWs' daily activities as well as taking statistics of the reach of service relating to patients consulted and cure rates.

Following Sister Reid's interventions, the CBWs now receive a stipend of R500 provided by the Department of Health. The group have received training on the following courses:

- home-based care a 59-day comprehensive training which is now standard across South Africa;
- Direct Observation Therapy Short-course support;
- first aid;
- integrated management of childhood illnesses;
- HIV/AIDS and counselling;

<sup>3</sup> Marianne Reid has since left Mangaung Local Municipality and she is now a lecturer at the University of the Free State.

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- anti-retroviral treatment counselling and administration;
- refresher courses on a regular basis and as needs arise.

The Mangaung Local Municipality Health Division assisted the group in identifying training needs. The training has enabled CBWs to give support to professional nurses at the different clinics, including the following:

- basic health education to clients visiting clinics;
- outreach to communities:
- support communities with health-related problems;
- follow up of clients who are not able to attend clinics due to ill health;
- provide home-based care for clients identified by professional nurses eg wound care and dressing;
- follow-up treatment of defaulters on medication;
- administer TB medication to patients at the clinic and at their homes;
- assist professional nurses to identify patients who are eligible for grants;
- the CBWs have received debriefing sessions from students studying Psychology at the University of the Free State who meet the CBWs monthly.

According to Golang Batcha's constitution, the CBWs are expected to work a minimum of thirty hours per week, four days a week. However in practice these volunteers work five days a week for almost eight hours a day. On average CBWs hold 237 health education groups/talks every month and attend to an average of 4-5 TB patients every day doing Direct Observation Therapy Short-course support (DOTS). This is an initiative by the Department of Health to help ensure that TB patients actually do take their medication and that they get the support needed to finish the course<sup>4</sup>.

The main motivating factor for the CBWs, especially those who remained, is that they see the direct impact of the services they provide. An example of this is that since working with TB patients the TB cure rate in the seven clinics has increased. With regards to HIV/AIDS more people are coming to test and, of those who have tested positive, a significant number of them are living with a positive attitude.

<sup>&</sup>lt;sup>4</sup> Interview with Sr Nuku Moshe TB Co-ordinator Mangaung Local Municipality, October 2006

Over the years some of the CBWs lost hope in being involved in the group as volunteers as there was no direct tangible benefit to them as individuals. They left the organisation to find employment opportunities elsewhere. It would seem these CBWs wanted to use their volunteering as a stepping stone for greater opportunities. Some of the remaining volunteers felt that some of those who left did not have a passion for working with people, especially the sick. Other CBWs who left Golang Batcha were chosen to take up training posts as assistant nurses. This is a positive outcome because people can not be expected to volunteer their services forever. Although this places major strain in replacing and retraining new volunteers, the executive committee has discussed the possibility of taking in new young members. This would help young people live responsible lives by making a social contribution to their communities and helping them gain a wider range of experience.

Through the research we were able to refine the reporting format of daily activities. Through representation on the CBW South African Steering Committee, Golang Batcha is recognised by Mangaung Local Municipality Health Directorate. Golong Batcha's co-ordinator was given a telephone pin code to gain access to the phone in the clinic to help her in organising logistics for CBWs field work and referrals to other health centres.

In 2006 Golang Batcha made a breakthrough when they wrote a letter of concern to the Provincial Premier, Mrs Beatrice Marshoff and the MEC for Health Mr Belot. Through discussions with both key policy makers, there was a public promise that CBWs will get a stipend of R1,000 from June 2006. Indeed, in a recent interview with Theresa, the chair of Golang Batcha, she indicated that they are now receiving the R1,000 per month, as a direct intervention they made.

#### 3.2 Selection criteria

Initially membership grew using a 'snowballing' method where people called each other. At the time volunteering at the clinic was desirable. When the number reached 87, the members introduced a clause in their constitution not to take new members as they felt that it was costly to train new members. In recent years the number of CBWs in the organisation has decreased dramatically, as some left to pursue employment opportunities and others died. Currrent members still maintain that the do not want to take new members. Methods of selection have been *ad hoc*. Perhaps it is necessary to have some kind of screening process to draw in people who feel committed to the project and its goals. This does not mean people should not receive some kind

of stipend or other tangible benefit, but building commitment to a social project must also be supported more systematically. It is clear that Golong Batcha require assistance in developing organisational procedures and structures that allow the organisation to recruit and retain new members rather than gradually dwindling to a handful of volunteers. There is an important role in this process for building stronger links between Golong Batcha and the formal structures of the health delivery system in this regard.

#### 3.3 Training, support, supervision and accountability

Golang Batcha members are all trained in home-based care, Direct Observation Therapy Short-course support (DOTS) and HIV counsellors. They receive monthly in-service training on an identified topic. This topic is then used during health educational talks for the rest of the month. Despite the comprehensive training programme, support to trained workers in the field poses a serious challenge; a shortage of staff has resulted in a lack of sufficient support after training has been completed.

The accountability structure currently in place is through the Executive Committee to which Golang Batcha CBWs are accountable. The executive committee is guided by the organisational constitution and monitors activities of members and disciplines members if needed. In the clinics where the CBWs are placed they report their activities to the designated TB nurse. CBWs collect monthly statistics of patients consulted and the status of the patients and these are forwarded to the Mangaung Health Directorate. A professional nurse in the clinic where a CBW is assigned identifies clients in need of assistance by the CBW and receives and monitors feedback on client care (Khanya 2004). The nurse in charge of home-based care projects (at municipal level) coordinates all efforts of the Executive Committee and the professional nurses in clinics send monthly claim forms to the Department of Health (provincial). The CBWs report directly to the TB nursing sister specifically for TB patients. However the heads of all the seven clinics are aware of the CBWs who are placed in their clinics. This is not a formal relationship because the CBWs feel that they do not know how they fit into the clinic structure and that the relations with other nursing professionals is on an *ad hoc* basis and sometimes dependent on individual personalities.

Mangaung local municipality Health Directorate, where the seven clinics from which Golang Batcha operates from, renders a service at local government level and not at provincial level - where the Department of Health is situated. CBWs do not report to the provincial Department of

Health, although stipends are received from this department. Further, there is no official agreement between Golang Batcha and the department and as a result communication channels are weak and decisions are not reached quickly.

Golang Batcha is not seen as a community-based organisation but rather as an organisation that falls under the Mangaung local municipality. A formalised and transparent relationship would benefit and also provide the framework to retain CBWs for a longer period.

#### 3.4 The contribution of community workers to participatory processes

Golang Batcha forms part of a consortium of home-based carers called Ngenani Emxholweni, an umbrella organisation for organisations providing home-based care in Bloemfontein (Khanya-aicdd 2004). Home-based care is presently rendered by CBWs registered or known to the Departments of Health and Social Development, as well as by groups or individuals not known to the departments. A Bloemfontein home-based care forum was established in 2004, with the main aim of creating a communication network between the Department of Health and Social Welfare and service deliverers. A database of CBWs was also to be established and the goal was to link CBWs with services that would enhance the work that they do. For instance the CBWs help in identifying people who are in need of welfare support and they often encounter difficulties in linking people with the relevant services/departments. CBWs believe that they face these difficulties because they are not recognised as service providers but only as volunteers by government. There are discussions in the departments of Health and Social Development to deal with these issues, but this is still in an early phase of development, with irregular meetings taking place. The group receives guidance from the Health Division of Mangaung Local Municipality in terms of monitoring and implementing services.

CBWs have links with the social worker responsible for the seven clinics. According to Golong Batcha co-ordinator, Theresa Davids, this is a good relationship because it means that there is always follow-up on referred cases. Some of the cases that CBWs encounter in the field go beyond the scope of health and welfare responses. In such cases the CBWs make efforts to link with other institutions such as local ward councillors. To date this has been an *ad hoc* relationship. In this case the CBWs feel that they are just seen as lay members of the community and yet the service they render is complementary to local government services. Some CBWs have tried to take a proactive role in participatory processes in their localities but this has proved to be unproductive. Ward

councillors as well as ward committees who are the elected leaders as the interface of government and communities seldom recognise the work of the CBWs. Instead there seems to be too much politics around community-driven development with recognition only afforded to youth who are affiliated to political parties.

The official introduction of community development workers (CDWs) who are placed in local municipal offices and are paid a salary further confuses the situation. CBWs perceive that the work of the CDWs, however important, invalidates the work of CBWs. In principle there is a commitment from national government to develop forms of institutionalised co-operation with civil society at local government levels, to ensure the ward committee system functions in relation to legislation. CBWs expressed a need to be considered for positions as CDWs because they have gained in-depth understanding of the health and socio-economic needs of their communities. Focus group discussions with patients receiving services from the CBWs revealed that CBWs are seen as a resource for information on how to deal with government especially on health, social welfare issues and registering for deaths, births and other related matters.

# 4. 'Getting institutions right' for pro-poor development

It is evident from observation that CBWs cannot function effectively without a formal link to a service provider. There is need also to identify persons or organisations to provide assistance in monitoring and providing clinical guidance, and for training. The current institutional structure is shown in table 1.

Interviews with CBWs and their patients established that most of the ward councillors where the CBWs render services are not aware of the existence of the CBWs. There is a perception that CBWs are part of the nursing structures and this is enhanced by the uniform the CBWs wear as they do home visits to patients. It is important that Mangaung local municipality acknowledges and recognises the efforts of the CBWs, especially because the CBWs report directly to the Health Directorate in the municipality.

Table 1: Current institutional structure for CBWs in home-based care

Stakeholder	Role
Mangaung local municipality	Infrastructure services
	Training
Free State Department of Health (TBB directorate)	Stipend payment
	Career pathing
Private sector (this is on an ad hoc basis)	Training, sometimes uniform
HBC Consortium	Networking
Hospice / ATICC	Training

Source: CBW National Workshop report 2004a

#### 4.1 The role of the state in service delivery

In 1997 the Ministry of Health tabled the White Paper on the Transformation of the Health System in South Africa (Department of Health 1997), in parliament. The White paper deals with the transformation of the health services to reduce the high levels of social inequality in health. The aim was to introduce a strong shift towards universal and free access to comprehensive health care, and shift the disproportionate level of preventable diseases and premature deaths in certain segments of the population. A constant theme of the policy document is one of reallocation, evident in the call to shift resources from tertiary services in metropolitan areas towards overcoming the inadequacies of hospitals and clinics in rural areas. The White Paper recognises the importance of knowledge, information and evidence by stating that health research must be linked and integrated into planning, policies, programmes and implementation.

CBWs are not integrated into the delivery system and often feel excluded from the mainstream health service delivery system. While there is an appreciation on the part of government on the work the community health workers do, there is no arrangement to recognise them as part of the formal system. Furthermore CBWs perceive the introduction of CDWs as invalidating and replicating the work they have been doing for many years. Perhaps it is time for some engagement with the state on community worker models, using the lessons of CBWs to shift the process to a more comprehensive bottom-up process guided by expressed needs and desires at community level. This requires the strengthening of ward and municipal participatory planning processes, the strengthening of ward committees - especially to move away from a political,

partisan approach to development and towards an approach more rooted in the practical requirements for development at ward level. However these structures and processes have to be imbued with a philosophical outlook that makes officials and volunteers alike, at all levels, servants to the population living in their area.

#### 4.2 The role of the state in participatory processes

Ward committees have been created as the recognised representative structures in South Africa and municipalities can choose to adopt a ward participatory model. The ward committee is legally meant to serve as a link between the community and the local municipality through the ward councillor. The introduction of the IDP process was another initiative by government to ensure that communities were integrated into the planning process, that real community needs were reflected in the plans of the municipalities and that the priority needs of communities are budgeted for. However in the case of Golang Batcha they do not see the role of ward committee members or the ward councillor as helping facilitate their activities in the community. In fact CBWs often feel that they are being exploited because they are often called to community meetings just to fill numbers. Although some Golang Batcha members have participated in the ward planning process this was seen as a once-off event and there was no follow up with communities. There is need to integrate CBW activities into ward and municipal plans and planning processes and to encourage the spread of the CBW model into other sectors or arenas of delivery. The CBWs, supported by other organisations, could play an important role in facilitating this process starting at ward level.

# **Conclusion: Impacts and sustainability**

Since becoming volunteers in the health sector the CBWs have experienced heightened awareness of the issues relating to HIV/AIDS. These issues range from better understanding of the condition, how to prevent transmission, and care and support for the infected and affected. CBWs are more tolerant of HIV-positive people and recognise that other HIV-related illnesses such as TB can be cured with good health management. CBWs report that, prior to gaining in-depth information about HIV/AIDS, they were ignorant and classified HIV/AIDS as a death sentence. They also reported having perceived HIV-infected people with pity. All that they've learned from

their voluntary work is applied in their own personal life. With regard to stress, the CBWs believe that through the voluntary work they have come to develop stress management strategies as advocated by the psychology students from the University of the Free State.

The intervention of the CBWs has assisted in reducing the TB interruption rate from 19.7% in 2000 to 13.8% in 2002 due to Direct Observation Therapy Short-course (DOTs). The work of the CBWs is well recognised in the province, and Golang Batcha received second place award in the Philane Awards for TB management in the Free State (Free State Department of Health 2003). Interviews with TB nursing professionals established that the service rendered by the CBWs has enhanced their work greatly and that they credit the increase in TB cure rate to the CBWs. The nurses added that to further ensure sustainability of this success it would be advisable to increase the number of CBWs in Golang Batcha.

Action-learning research with Khanya-aicdd has helped the group to keep diaries where CBWs started reflecting more deeply on the work they do, how they do it and the importance elements from these. A video was produced featuring the work of Golang Batcha. This has inspired CBWs to work harder, because through the video the clients of CBWs have had a voice and it is the first time the CBWs can authentically show others evidence of their involvement.

Despite these positive aspects of Golong Batcha's experiences, it is apparent that the system is not functioning in a sustainable way. CBWs are not integrated in a structured way into formal health delivery systems. Their use is heavily dependent on the personalities of the formal staff they happen to interact with at a particular clinic. Poor communication channels between the health department and Golong Batcha makes formalisation of decisions cumbersome and slow. The top-down community development worker concept threatens to displace CBWs who work voluntarily in the communities. Moreover, due to its voluntary network nature, the organisaiton has lost key staff members and does not have the support to develop adequate procedures and structures to retain members or increase the number through recruitment of new ones. It must be acknowledged that volunteers have personal as well as social interests in participating in voluntary projects such as Golong Batcha. Training and the small amount of payment received acts as a useful incentive to carry on voluntary work but also as potential resources to advance into more formalised employment in the future. It would serve the department well to draw people in as volunteers but over time formalise their positions while retaining the bottom-up culture of accountability to the communities served.

To summarize, the Golan Batcha CBW system faces the following challenges:

- CBWs travel long distances on a daily basis and have to cover wide geographical areas. For
  example at Batho clinic there are only two CBWs who have to do home visits in the areas of
  Batho, Bochabela, Matlhomola, Silver City and ten big informal settlements;
- Safety is a big issue especially because most of the CBWs are women. There is a potential danger of assault, rape and theft;
- The personal wellbeing of CBWs is often overlooked because they also have to put food on their families' tables. Consequently the R500 stipend is not enough, barely covering their travel not to mention making contributions to the clients they visit. The CBWs often feel disempowered when they take into account the financial remuneration they get for the work they do. Some of the CBWs are the main bread winners for their families;
- The support from the Departments of Social Development and Health remains at a fairly low level. Promises are regularly made that the stipend will be increased and that people will get food parcels, but to date nothing has materialised;
- CBWs cannot offer quality home-based care because there are only two home-based care kits to cater for the whole team of 21 volunteers;
- CBWs are not able to apply some of the knowledge acquired through training because of lack of support from some professional nurses;
- Shortage of professional nurses in some clinics creates a problem regarding supervision and support, especially for monitoring the home visits done by CBWs; This is due to transport problems in the municipal Health Directorate;
- There seems to be no principles of *ubuntu* (mutual respect, humanitarian ethic, unity) in some clinics where professional nurses treat the CBWs with disrespect. This amounts to emotional abuse and lack of collaborative effort in supporting the poor.

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# Appendix: CBW diary extract

## 2005-Theresa Davids Batho Clinic (Co- ordinator Golang Batcha)

#### April 07

Today I started late because the rain was pouring. Its very hard for us to work on rainy days, we are walking from door to door. The rain makes it difficult especially in Squatter camps were the roads are muddy and the roads are bad. We do not have protective wear for bad weathers like wind breakers, shoes, umbrellas. We get bothered when the weather changes. We know that on windy, sunny and rainy days we have to work because its our duty. I started giving my patient treatment at 08:30 and stayed for 15 minutes. I finished my rounds at 10:30. Afterwards I went to the clinic to help with administering TB medication I finished at 12:30 and went back home.

#### April 11

I walked from Phahameng to Park Square and started seeing patients

3 in Park Square on the same street

3 more in 3 streets about 3 streets apart

#### April 12

I go to see one of as usual, but when I got the first patient I find the door is locked. I wonder where the people of the house are, there is not even one child outside, the door was locked I became worried because this is a very sick patient who is a bedridden. I go past and see other patients. When I got the clinic I give the report to the nursing sister in charge about the patient that I didn't see. I did not get any report on this matter.

#### April 13

I go on my rounds visiting my patient, the house is still locked. I enquired from the neighbours who said that I should ask the tenants in the backyard, who tell me that they had not seen the people in the main house. I go the other patient on the same street and ask about the whereabouts of the previous patients. They told me that the relatives of the patient came to take him as they allege his wife was not giving him proper care and she drinks a lot and steals the man's money. I become more worried because there are two children who are under the age of 5who are suffering from TB I don't see the wife and I become more worried.

#### April 14

Meeting with group leaders to discuss how we discipline members who disobey the rules and regulation of the constitution. Lindi of Khanya came to observe how we run meetings.

#### April 18

All the group leaders except the one from Thusong clinic were at the Municipal building in town to complete payment forms. We tried to call other people who did not complete their payment forms but their phones were off. The researcher from Khanya was also present. There were people who did not get paid, this is sad because these are active members. We do not know the reason they did not get paid.

#### April 19

I was supposed to be accompanied by the researcher when I visit my patient but we had to change plans because one of my colleagues asked the researcher to go with her instead. This upsets me a lot and my day was spoilt. I went to all 6 of my patients but one I didn't find.

#### April 20

Today was my day to do my rounds with the researcher. The first house is one of the patient whose family had taken him away, today the wife is there. I ask her why the children were also taken away because they are still young, under 5 years. She says that she is sure that the children are in good hands. The researcher asks the mother about going to the social development offices for support. We visited all our other patients who were very happy to meet the researcher. They all tell her how happy they are with how we treat them, and that the work that we do is very important for their health. They say they love the fact the nurses now can come to their homes and not just sit in their offices. The patients refer to us as "sister" because they think we are professional nurses. This was a great day for me because it shows that the time I spend going from door to door is actually appreciated. The researcher ask them if they know how much we earn and when they hear, one patient said its such a wonder that these people who take good care of us do not get paid a lot of money but they never treat us bad. Afterwards we went to the clinic where I gave a health talk to breastfeeding mothers there were 30 mothers and the sister could not attend to all of them, some of them were told to leave and come the next day. Afterwards I had a private interview with the researcher. She asked me how I manage my duties as a chairperson and co-ordinator for Golang Batcha on top of doing my DOT support. I mean its stressful for me because I always struggle with money for transport and making phone calls, I end up using my own money for all that. I get a stipend of R500 per month and my husband is not working, I have two children one on Grade 8 and the other one in Grade 2. I pay R80 school fees for the older one and R40 for the younger one per month. And as for keeping my family going I am always in debt because I can't afford.

#### April 21

I visit all my patients, all of them are fine and talk about yesterday's visit with the researcher. They say that they appreciate it because they managed to talk about what they see Golang Batcha is doing for them. They say that they wish we can continue in what we are doing and hope that we could can a better payment. They say that they wish that the Minister of Health can come to the communities and see the good work that volunteers do for them.

#### April 25

Some of my patients are now cured and these were on the 6 months and the others were on the 8 to 9 months treatment. I went to the nursing sister to allocate me more patients. I am not so happy today because I did not get my stipend, this stipend thing is not regular. Some months you get and others you don't but we do the job everyday. I had to borrow money to attend meetings and now I have nothing.

## April 26

We were expecting the researcher to come, but she did not pitch. We gave some health talks on cancer of the womb and breast cancer and told them mothers how to check for the signs of cancer. We wanted to make mothers aware of the dangers of cancer.

#### May 2

We prepare ourselves to go to work at community halls. We were placed at Batho hall near the clinic. We worked at the clinic for the first 3 days and started at the all pay community hall. I told my patient that I would only see them in the afternoon that week because I was going somewhere.

#### May 3

Social Development asked me to give 10 names of Golang Batho. They told me they wanted people who are hard workers to do the job. The job title was all-pay pension committee member even. We were going to work as volunteers this month we work for four days one day to make five at social development. We help old people to go first to the machine for their payment. Very sick people are not to stand for a long time, wheel chairs help them go to the machines without wasting time because they form lines in cold weather and rainy days.

This happened in community hall s at Batho hall, Paradise hall and Thusong Hall and social development the last two weeks of the end of the payments. So we are four groups supposed to be 5 groups so the last week all the groups are alternating, one day at social development. As leaders we go and report this to Sister Reid and she said it's alright. On Saturday they told that there are small projects like helping people the go for support grant so that they don't stand and wait for a long time. They also said that if we work quickly they will open two stations for our people of Golang Batho.

#### May 4

It was our monthly meeting at at 9h00 at Batho Clinic.

#### May 5

We work for days in the community hall.

#### May 9

I start going to my patients to give them their treatment. They were very happy again some of them saw me in the community hall and asked me what I was doing there. I told them I was trying to make more money because I can't afford my house. For that money even if I become permanent I will leave the clinic work and continue with Pension committee work still as a volunteer. We had to sign a contract to continue, but we can do both if we want. But for me the money from the new work is better I can take the new one and leave the clinic

#### May 10

All pay day at the hall. Our patients know that we go for R500, so they say why are not getting paid for the job. We help them not to go and stand in long queues at the clinic and at the hall when they collect their social grants the job we are doing is wonderful.

#### **May 16**

I see my patients, one was very ill, and then I went to the clinic to report that his feet are swollen. The nursing sister gives me paradoxine to give the patient. When I got to the other patient to give the last sputum bottle, I find a problem of a lost card. Then I went to report to the nursing sister, who said that it is not a problem to make a new card.

#### **May 17**

I went to see all my patients then I went to the clinic where I met a nursing sister Moipolai. She asked the CBWs to give a health talk on HIV/AIDS. The clinic was full on that day and people seemed to be concerned, afterwards we gave a health talk on ARVs. Sister Moipolai encouraged us to do regular health talks at least 3 times a week. Afterwards we did a

recording of the TB statistics of the previous month. I have 7 TB patients and two of them were cured.

#### **May 18**

A meeting with Mrs Selaledi a councillor who is heading the health and environment portfolio within Mangaung Local Municipality. We tell her our problems as an organisation, we have been volunteers for over 5 to 6 years and we find it disappointing when we hear people from other areas such as Xhariep saying they earn R1000 per month. The talks about R1000 stipend we have been hearing them since April 2004. We later went to a meeting hosted by the Provincial Department of Health and we meet Mrs Letitia Nomtshongwana, Puseletso Mohapi, Shirley Hugo and from Golang Batcha it was Myself, Keneiwe Motenane, and Marie Motse. The people from Health told us that to be a volunteer one has to be between the ages of 21 and 34 or 35. They told us that the certificates we received after the trainings we went to cannot be credited. They further told us that they only know Golang Batcha as DOT supporters and nothing more. When we asked about the statistics that we take each month of the health talks, counselling sessions and Home based care, they said they know nothing about those. This was very disappointing because we take statistics every month and send it to Sr Reid's office. We were told that the DOTS stipend is taken from the HIV/AIDS budget and that the Department rely on funding from other countries. We heard other rumours that Mangaung Local Municipality is not in good terms with the Department of health. Apparently the clinic committee members are the ones who are going to benefit and the volunteers are to move out of the clinic. So we want to know for us we have been doing DOT support for 5 years is this their Thank you to us! After that we took our statistics to Sr Reid's office.

## **May 20**

We were prepared to have the first meeting at 09.00 and Mrs Selaledi a councillor working in the Municipality was having another meeting elsewhere. Her P.A Oscar apologised on her behalf and the meeting was cancelled.

#### May 23

TB Campaign at Batho clinic Park Square and Sekgopi Square. Collection of sputum to all those we give bottles. On the first day there were 18 people, we had to give 25 sputum bottles. We do the job very smooth, because we start with a TB health talk then we ask the people to take the 2 bottles and to spit in it early in the morning.

All the carers were called to the civic building for the meeting about food parcels, but Golang Batcha carers were not called. The meeting was called by the provincial department of health, being a big organisation we were not informed. We don't know where we are so it is a question mark. We want to know where we are, who we are. Are we recognised or not? Because these days Batho was doing sputum campaign for TB but other carers from other clinics were free to go.

#### May 25

We collect the sputum bottles we had left the previous day. There were 27 bottles it was the last day of the campaign, it was so successful. We do not find any difficulties because they always see me in those settlements, as it is where I work daily. So I informed them the previous day and they said they wanted to test for TB. It goes very smooth, they volunteer themselves to be tested and I think we did more than 50. Every clinic for that campaign had to do 50 sputum bottles. It goes very smooth.

#### May 30

We were busy preparing for the 31<sup>st</sup> with people from the department of health. They told us that Mrs Manto Tshabalala- Msimang is also coming so everything must be there. The meeting was at Seisa Ramabodu, we were promised to get T-shirt, cap and apron to show that you are a marshall. White T-shirt of HIV/AIDS, anniversary yellow cap, blue and white apron, so that people can respect us when we talk to them. Go this way, sit here, go out this way. Everybody was having caps all those who attend the march.

#### May 31

There was a march 12 people from Golang Batcha and MUCPP were marshals from B.P Library to Seisa Ramabodu stadium. We had to meet as early as 7 o'clock to arrange ourselves. All in all we were 30 marshalls. We start arrange tables and chairs then we arranged the duties for ourselves. Others were to show cars where to park, others inside to usher the guests where to sit, others to show the bathrooms for men and female and keep order inside the hall. It was fine everything goes well .Nothing was said about volunteers. Good about traditional healers, health workers like Professional nurses. Even the traditional healers have an item to sing and the schools were recognised receiving certificates, it was tobacco day. Warning people to stop smoking, as it causes cancer. If a person smokes in front of children or in public, children can take that to the police station, you smoke inside the house they have right to call the police and it's a case because it is dangerous for those who inhale the smoke of cigarette. At least the MEC of health Mr Belot was there and delivered a speech on tobacco and cancer. Clinics also received certificates and Pelonomi choir was there singing very well.

#### June 1

Forum at City Hall

Changes of the program

Diamond with speech

End of diamond term

1<sup>st</sup> annual meeting

In HIV/AIDS prevention is better than cure, but we also need a cure. Executive committee must have 5 representatives for all organisations. General meeting, everyone must have representative. There were 10 nominees, Golang Batcha as also there but we didn't win the votes. There come 5 names from other organisations, Chairperson, Secretary, Treasurer and two additional members.

We have two meetings and the one of Golang Batcha. We meet somebody from Tshepong based at National hospital. She wants to make us aware about abuse of men and women in the house, child abuse, and grants for children. Things that make grants process to delay is that children don't have birth certificates, clinic cards and social workers take time to attend these issues. People who take responsibility of these children suffer the consequences for these kids. If government can speed up all those things. Because we also meet those people and we refer them to social development to do an affidavit to prove the statement is true or they may go to Tshepong to report the matter.

#### June 2

Today we receive all the campaign results all of them were negative. We had targetted Park

Square where people still live in shacks. They are always sitting together drinking beer. So we had talked amongst ourselves that maybe we will find many of them having TB because they smoke zol, puffing and passing to another and drinking Bantu beer passing also the bucket to another.

#### June 6

We are helping in Allpay as pension committee. To help the aged sick people to not stand a long time in the lines. We take them forward so that in Allpays there must be no case. We are not allowed to sign incident forms because it's a case. As we are volunteers we have to identify people and help sick people with epilepsy, sugar diabetes, on wheelchairs to go straight to the machine.

#### June 7

Batho clinic and Opkoms clinic with Lindi of Khanya and Golang Batcha patients.

So that evaluation of patients was so important to us as volunteer, we heard that our community like what we are doing, then they call us sisters but we told them that we are volunteers. So they like us to get position because we are fieldworkers. We know community needs more than sisters, so the municipality must take us as permanent staff. Because when they come to the clinic they come as early as 07.30 and sit up until 14:00 sometimes they are postponed to the next day. Sometimes they go to the clinics for two full days and only get help on the second day. We were tired as volunteers for 6 years now the patients give us strength now they give strength to us. We feel proud of that, to hear some people are focusing in this programme of volunteers because even counsellors they know about us but they take this for granted. They say this is happening but they don't come to us to discuss the matter with us. So this day was so wonderful to us because we were 5volunteers and 5 patients.