# People living with HIV / AIDS in a context of rural poverty: the importance of water and sanitation services and hygiene education

## A case study from Bolobedu (Limpopo Province, South Africa)

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### Abstract

In South Africa, HIV/AIDS is still approached primarily as a health issue, with interventions focussing mainly on prevention and treatment. The social implications and poverty dimensions of HIV / AIDS are recognised in policy, but have not yet been translated adequately into practice. Provision of affordable, accessible and reliable public services is essential in supporting health maintenance and reducing stress for people infected and affected with HIV/AIDS. Reliable delivery of good quality water and sound basic sanitation are critical in reducing exposure to pathogens to which HIV-positive people are particularly vulnerable. Where water services are inadequate or inaccessible, the time and monetary costs of accessing good quality water in sufficient quantities are high, particularly for HIV-infected people and their care-givers; similar points apply to sanitation. This case study, which focuses on three settlements in the Bolobodu area of South Africa's Limpopo province, confirms these points.

The research found that discussion of HIV/AIDS issues remains taboo for the majority of people. In two of the three settlements, the breakdown of public water services has meant that residents have reverted to unprotected water services. This has significant time costs, and is particularly onerous for households directly affected by HIV/AIDS. It also impacts on the time available to care givers to provide support to needy households. Public health messages around 'healthy living' for People Living with HIV/AIDS (PLWA) focus on nutrition and exercise, with no reference to the role of good basic hygiene, water and sanitation in minimising exposure to pathogens and safe-guarding health. The importance of good nutrition, supported by food gardening, underlines the need to make water available for productive purposes to improve the livelihoods of impoverished households and maintain good immune functioning.

The study recommends that the water sector pays far closer attention to the specific impacts of inadequate services on those who are HIV positive, works to strengthen targeted multi-sectoral initiatives - notably with the health and agricultural sectors and in schools - and has a key role to play in promoting closer integration of support and training to care givers.

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## Section 1: Contextualizing this case study

### Introduction

HIV/AIDS is the largest pandemic the world has seen. By the end of 2002, an estimated 42 million people were living with HIV/AIDS globally. In 2002 alone, there were an estimated five million new infections of HIV and 3.1 million deaths due to HIV/AIDS (UNAIDS, 2002a).

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HIV/AIDS is most prevalent amongst adults. Its impacts are felt most directly within their families, but it affects broader society as well, as adults are the most productive people in society. Thus HIV/AIDS is not only a health issue, but a social issue too. The pandemic has significant poverty dimensions to it, which are elaborated in Barnett and Whiteside (2000).

One sector affected by the HIV/AIDS epidemic is water and sanitation. HIV/AIDS impacts on the provision and sustainability of services at several levels. Equally, the pandemic puts particular demands on these services, by fore-grounding issues of access and affordability.

Recently the IRC published a Thematic Overview Paper (TOP) on the subject of HIV/AIDS and its links with Water and Sanitation (Kamminga and Wegelin-Shuringa, 2003). The TOP reviews the implications of HIV / AIDS for the water sector, and highlights areas of particular concern:

- Physical access to water and sanitation by people infected by AIDS and their care-givers
- Participation in decision making around the services by people infected by AIDS and their care-givers
- Problems in management, operation and maintenance of water services, which affect sustainability
- Changes in demand for services (quantity, quality, uses and types of services)
- Integration of life skills-based hygiene education and HIV/AIDS awareness raising
- Agencies' capacity being affected and coping strategies and policies (internal management, prevention, impact mitigation and service provision)
- Gender, age and poverty dimensions of HIV/AIDS, as they relate to water and sanitation services

The TOP was essentially a conceptual paper. This case study seeks to explore the human dimensions of the linkages between HIV/AIDS, water supply and hygiene, through the experiences, problems and coping strategies of the people, communities and agencies directly affected.

The study does not address all the issues identified in the TOP. Nor does it follow the sequence of issues outlined above. It locates localised service and support challenges in the context of far-reaching institutional transformation and transition in South Africa. Implementation of ambitious national policies is constrained by poor inter-departmental co-ordination and the practical realities of decentralisation to municipal structures which themselves are struggling to fulfil the roles assigned to them, particularly in rural areas. Notwithstanding these structural difficulties, the study highlights the impacts of inadequate service provision in the water sector on those living with the HI virus, and calls attention to their particular needs.

### *Case study aims, objectives and target audience*

The aim of the field case study is to provide insight into the extent to which the issues addressed in the TOP are important and relevant for both service providers and consumers. In addition, it aims to describe the coping mechanisms that have been developed for water, sanitation and hygiene service delivery and, from the perspective of the infected and affected water users, how they access these services.

The compilation of the case study has three objectives:

1. Providing case illustrations of key issues identified in the TOP from the perspective of those infected and affected by the epidemic;
2. Learning from people concerned, in communities and service agencies, about their experiences and recommendations for strategies related to water supply (domestic and productive), sanitation and hygiene at household and community level and at agency level;
3. As a derived product, providing material for advocacy on the subject, not only for the water sector, through emphasizing the multi-sectoral nature of HIV/AIDS. Stories of people's experiences and coping strategies can help make policy makers, programmers and donors more aware of the interlinkages between the sectors and promote adjustment of strategies and programmes where necessary.

The target audience for the case study report is water, sanitation and health professionals in the South and the North working for national and local governments, NGOs, sector information/resource centres, private sector firms, UN agencies and multilateral and bilateral support agencies, as well as journalists working in the development sector.

## Methodology

### Site selection

In South Africa numerous local initiatives have been undertaken to deal with the HIV/AIDS pandemic. They provide rich material for instructive lessons. This case study focuses on parts of one extended settlement where concrete activities are underway, and where local government, NGOs, CBOs and the private sector have combined their efforts and resources to tackle the pandemic and its impacts.

Bolobedu is a large 'tribal area' of close to a million people falling under the jurisdiction of a traditional leader, or chief, in Limpopo Province. It straddles two Local Municipalities (LMs), namely Greater Tzaneen LM and Ba-Phalaborwa LM, both of which fall under the Mopani District Municipality. Bolobedu is made up of a number of dispersed settlements, called 'blocks'. Field work and interviews were conducted in three blocks: the villages of Wally, Mawa and Mookgo. The area is predominantly agricultural, and the main source of very limited employment is on neighbouring citrus farms. Few people are involved in subsistence farming. Residents rely for income primarily on pensions and remittances from migrant workers. The area is reasonably representative of many rural communities in South Africa.

### Research activities

The research included the following activities:

- Site selection and making contact with organisations already active in the field of HIV/AIDS in the area;
- Preparation of data collection tools;
- Semi-structured interviews based on a of list guiding questions with staff of one of the NGO's, the co-ordinator of the Greater Tzaneen Municipality AIDS Council (GTMAC) and a nurse, working in the village clinic;
- A review of project documents and municipal grey literature;
- Field visits to the villages of Wally, Mawa and Mookgo, where the following activities were undertaken:

    - Review of local water and sanitation facilities, working together with members of local community structures to explore the type and state of water and sanitation infrastructure, coverage, continuity of supply, water quantity and quality available, consumption patterns, and the use of water for different purposes. During the village walks informal talks were held with community and CCC members.
    - Focus group discussions with the following groups: representatives of different community bodies, home-based care volunteers, orphans and vulnerable children, people living with HIV/AIDS (including home visits to bed-ridden persons), and an HIV/AIDS awareness youth group.

Focus group discussion with home-based care volunteers, Mookgo

A guide was prepared for the focus group discussions which was adapted for each grouping of people involved. The guide also included the use of some participatory tools, namely: time lines, daily routine exercise, and an assessment of 'satisfaction levels' with local services.

- After each meeting or interview, feed-back was given by the research team to the persons with whom the meeting was held – including a representative of the Municipal HIV/AIDS council, the NGO staff and different community organisations.

Regional DWAF perspectives are not reflected in this case study. Repeated attempts to meet with a senior regional representative of DWAF proved unsuccessful.

#### *Limitations on the research*

HIV/AIDS remains a taboo topic for many South Africans, for reasons ranging from fear of AIDS and its health implications, to fear of prejudice and stigmatisation. As in many other countries, research in the area needs to be conducted in an environment of trust, preferably using existing networks, where people are willing to disclose their status.

In the course of this research it became evident that those who are willing to disclose their status and participate in focus group discussions of this nature are not necessarily representative of the broader range of experience and opinion among those who are affected or infected by the virus. They are simply those who have risen above the taboos and stigma attached to HIV, in part thanks to the work of supportive community members and NGOs.

The use of participatory methodologies enabled people to be more open, and to reflect on their situation. The daily routines exercise, in particular, was valuable in highlighting clear differences in task allocations between men and women, and for those involved in home based care.

The research findings presented below rely on qualitative, not quantitative, data. It was not possible to source any reliable statistical information, even at municipal level. This means that firm conclusions on the extent of the pandemic, changes in demand for water services, willingness to pay for water services, and so on, cannot be demonstrated statistically and should be drawn with caution. Further quantitative research is recommended.

## Section 2: HIV / AIDS and the water sector in national context

### *National HIV/AIDS policies and initiatives*

South Africa is one of the countries worst affected by the HIV/AIDS pandemic. According to UNAIDS (2002b), by the end of 2001 an estimated 5 million South Africans were HIV positive. This figure includes 250,000 children. This means that 20.1% of adults between 15 and 49 years are HIV positive. A recent survey by the Human Sciences Research Council (HSRC, 2002) estimates that the adult prevalence rate is 15.6%. The latter study compared prevalence rates amongst different sub-groups in South Africa, and revealed that the rate of infection is highest in urban (informal and formal) settlements (21.3% and 12.1% respectively), as compared to rural areas (8.7% in ‘tribal’ areas and 7.9% in farm areas). Regardless of the precise numbers, the prevalence is alarmingly high

Following earlier government initiatives, in June 2000 the Department of Health launched the HIV/AIDS and Sexually Transmitted Infections Strategic Plan for South Africa, 2000-2005 (DoH, 2000). It has been revised further in 2003 (DoH, 2003). The overall goals of the Strategic Plan are to:

- reduce the number of new HIV infections (especially among youth); and,
- reduce the impact of HIV/AIDS on individuals, families and communities.

Broad strategies to achieve these goals include the provision of appropriate information, education and communication (IEC), increased access to voluntary HIV counselling and testing (VCT), improved STI (Sexually Transmitted Infections) management, and improved care and treatment for HIV infected people and support for their care-givers. Following fierce lobbying by activists and a Constitutional Court ruling, government is now phasing in a national Anti-Retroviral Treatment programme. The logistics of treatment provision and support are, however, daunting.

The Strategic Plan focuses action on the following priority areas:

- Prevention
- Treatment, care and support
- Human and legal rights; and
- Monitoring, research and surveillance.

These four focus areas are further sub-divided into 15 goals, ranging from reduction of mother to child transmission to surveillance of the pandemic.

The second priority area, 'Treatment, care and support', includes the objective of poverty alleviation to address the root causes of HIV/AIDS. Strategies here include using HIV/AIDS prevalence rates as an indicator for poverty, with co-ordination between different government departments, the private sector and global donor agencies to establish poverty alleviation and support projects.
Amongst the activities arising from this Strategic Plan has been the establishment of a South African National AIDS Council (SANAC), the highest government advisory body on HIV/AIDS- related matters. This body is chaired by the Deputy President, and consists of representatives of 16 government departments and 17 civil society representatives.

The Department of Water Affairs and Forestry (DWAF) is not a member of SANAC. However, a comprehensive refinement of national water services policy, the Strategic Framework on Water Services (DWAF, 2003) highlights some of the linkages between HIV/AIDS and the water sector. It notes that:

> *Lack of access to water supply and sanitation constraints opportunities to escape poverty and exacerbates the problems of vulnerable groups, especially those affected by HIV / AIDS and other diseases. A key focus of South Africa's water services policy should be on ensuring access of the poor to adequate, affordable and sustainable levels of defined basic water supply and sanitation services (the first step up the ladder).* (DWAF, 2003:1)

It notes further that 'health and hygiene education are particularly important in the context of the greater vulnerabilities of individuals and groups affected by HIV / AIDS.' (DWAF, 2003: 22). The Strategic Frameworks requires the following:

- Municipal Water Services Development Plans (WSDPs) must take into account the impact of HIV/AIDS on water demand
- Water and sanitation tariffs and subsidy mechanisms should be pro-poor and consider households affected by HIV/AIDS
- The best use of existing capacity in water services provision should be made, particularly in the light of potential losses in human resource capacity through HIV/AIDS.

This Framework was approved by the Cabinet in September 2003, and it is therefore too soon to assess the impact of these welcome policy statements.

## *The institutional context of water supply and sanitation*

The apartheid years continue to cast a long shadow over service provision in the Bolobedu area, with significant service backlogs still experienced in many areas. When the former Lebowa homeland was 'reincorporated' into South Africa in 1994, responsibility for water services was assigned to the Department of Water Affairs and Forestry. In terms of the new Constitution and municipal legislative framework, water services – including sanitation – are now the responsibility of local government. The larger municipalities are now designated as Water Service Authorities, responsible for ensuring provision of water services; they in turn enter a contractual relationship with a designated Water Service Provider of their choice, which could be the municipality itself, a public or private sector entity, or a community based organisation. A complex process of transferring infrastructure, funding and responsibility for service delivery from DWAF to municipalities is underway.

A number of community water and sanitation projects were undertaken by DWAF in the Bolobedu area, with local responsibility for operation and maintenance of water schemes assigned to community water committees. Residents were required to make a small monthly payment to cover the costs of service provision from a communal water point.

As part of its commitment to addressing the needs of the poor, a policy of free basic water is being introduced nationally, with 2005 as the target date for comprehensive implementation. The policy provides for the first six kilolitres of water consumed monthly by poor households, free, with the municipality responsible for funding the cost of this through cross-subsidies or grant finance from the fiscus. As will be shown below, introduction of the policy has led to confusion on the ground in some areas, with premature announcements by a local councillor that service payments would no longer be required – before municipal funding arrangements had been concluded. This has led to a complete breakdown of water services in one of the villages addressed in this case study.

With municipalities taking increasing responsibility for water services, the role of local village water structures has become unclear. One unfortunate consequence of this is that local capacity and willingness to operate and maintain water delivery systems is severely attenuated, leading to further problems with the reliability and quality of supply. This impacts particularly harshly on those who have AIDS-related illnesses.

Through municipalities, a national programme is underway to address sanitation backlogs with the provision of at least Ventilated Improved Pit toilets, and basic user education around health and hygiene and toilet maintenance. Relatively few households have benefited from this programme in the settlements reviewed for this case study.

### *Local HIV/AIDS policies and initiatives*

Most municipalities have set up local HIV/AIDS initiatives. Within the study area, the Ba-Phalaborwa LM has formed the Ba-Phalaborwa AIDS Awareness Project with support from three local mining companies. This project provides support to home-based care givers and offers AIDS counselling. It works with the Itereleng Educational Project, which undertakes awareness raising activities and community mobilization around AIDS. At municipal level, an HIV/AIDS co-ordination council has been established with representatives of the local government, NGO's, CBOs and the mines. The council is funded by the mines and the Nelson Mandela Children's Fund.

A similar effort has been undertaken in the Greater Tzaneen LM. In November 2002 the Greater Tzaneen Municipality AIDS Council (GTMAC) was established. This is a co-ordination council composed of a wide range of stakeholders, including several departments within the Municipality, NGOs, faith based organisations, youth groups, CBOs and medical personnel. Their objective is to disseminate information and co-ordinate services in the fight against HIV/AIDS. Activities focus on education, on prevention, food parcels for HIV-positive people and assistance in accessing health care.

Although the Department of Agriculture participates in the GTMAC to address issues relating to impacts on food production, little attention is given to small-scale vegetable gardening as a strategy to supplement the diets of people infected with HIV/AIDS. In neither of these initiatives has the role of public services – notably water and sanitation - in the fight against HIV/AIDS been made clear. No water and sanitation sectoral representatives or service providers participate in these initiatives.

The Greater Tzaneen Municipality recently adopted an internal workplace policy on life-threatening diseases (LTD's), which refers explicitly to HIV/AIDS. According to the co-ordinator of GTMAC, services rendered by the Municipality have not yet been affected by the HIV/AIDS pandemic. Even if this were true, it seems unlikely that this will remain true for much longer.

Municipal primary health clinics are modern and well-run, and play an important role in dealing with HIV/AIDS issues. Anti-retroviral treatment is not available yet at clinic level in the Bolobedu area, and thus treatment focuses on symptomatic relief and palliatives. Clinic staff are active in education around HIV/AIDS prevention, but the information presented is highly fragmented. TB, for example,

is one of the most common and deadly opportunistic infections associated with AIDS, yet no linkages are drawn between TB and HIV/AIDS. Similarly, no information is provided on the importance of basic hygiene practices – such as washing hands, using toilets, drinking safe water, cleaning water containers and practising good food hygiene – in reducing the exposure and vulnerability of HIV positive individuals to potential infections.

Social workers employed by the Department of Social Development play a vital role in providing food parcels containing vitamin-enriched maize porridge to those living with AIDS, orphaned and vulnerable children and others in need. Nurses and home-based care volunteers refer HIV positive persons to this department for support.

# Section 3: Research findings

## *General characteristics of the communities*

### Livelihoods

> **Caring for the sick**
> Elias is bed-ridden, and is extremely thin and weak. His family looks after him, with help from a home-based care group which provides him with food parcels and medicines.
> The family relies on the old age pension of his mother.
> The family has a toilet, but it is in a poor condition. His mother struggles to clean him when he soils himself, as he cannot move from his bed.
> His mother has a friend who brings water, but there is seldom enough. They rely on river water which they do not believe is clean or safe to drink.

The three settlements visited (Mawa, Wally and Mookgo) can be described as poor rural villages. They range in size from 450 to 600 households. Unemployment levels are high, with just 15% of the population estimated to be formally employed. Those with jobs work mostly as agricultural labourers on nearby citrus farms, on the mines or in nearby towns. A small industry was established in Wally in 2001, but the wages paid to its mainly female workforce are extremely low. There is little evidence of subsistence agriculture, although some people have livestock. The main sources of income are the government pensions of the elderly, supplemented for some with migrant remittances. Depending on water availability, people engage in food gardening. There are also some small business like shops and brick making. Good gardening and brick-making depend on water availability.

The ‘daily routines’ exercise conducted in each settlement indicated a significant difference between the activities of men and women. Women tend to have a very busy schedule. They rise early to ensure their children get off to school on time. Their men rise much later to find their food and water waiting for them. Some men who are not in formal employment spend their days tending livestock or collecting fuel wood for sale; others join their friends to share a beer, a discussion, a game of soccer or watch TV. Women, meanwhile, spend their days cleaning the house, fetching water, taking care of their families, assisting friends, relatives or the elderly in home-based care activities, and attending community meetings. Children might help their mothers when they return from school. Women head many households.

There is much evidence of mutual support between families, particularly where a family has lost their breadwinner to AIDS or other misfortune. Families with food share with those without, often providing a bag of maize flour to their relatives

The most pressing concerns in the settlements surveyed are high unemployment and inadequate public services. Problems identified include unreliable water supplies, the lack of regular transport to the nearby town of Tzaneen at affordable prices, the lack of sufficient clinics and the lack of a permanent police presence to reduce crime.

## Community participation and representation

Each community has a Community Co-ordination Council (CCC), which consists of representatives of different community committees, such as the youth group, the civic committee and the safety and security committee. In that sense, it is the highest level of organisation of the community, and is the body that meets with the ward councillor. The ward councillor chairs a local ward committee. The ward councillor in turn sits on a municipal representative council. Community organisation is not strong, and it seems residents are relatively passive, leaving all initiative to municipal and government representatives.

**Food gardening and other struggles**

Olive started a food garden in her yard when she realized she needed vegetables to boost her health. Her son helped her grow spinach and tomatoes, but it needs much water and attention, and her son isn't always available to help.
Olive's health declined rapidly in February 2003. She is now so sick she can do little for herself. Her son fetches water when he comes back form school. He collects the water from a standpipe near their house. She should pay R5 each month for this water, but the community still allows her to collect water when she does not have the money.
When the water is available her son fills every container he can find. When the standpipe is dry, she buys it from a private borehole for 50 cents per 25 litre container. When she runs out of money, her neighbours support her.
She does not have a toilet of her own, but uses a clean toilet at her church.
She needs to visit the hospital in Tzaneen from time to time, but struggles to find the R25 needed for transport.

Informants said that those who are ill cannot participate in decision-making around development issues in the community, and this is left to their relatives.

There is no recognised community management of the water supply. Some members of the CCC undertake discrete tasks, such as collecting money for payment of the electricity bill for the borehole and liaising with the DWAF-employed pump operator. Community members do not make collective decisions around water services, nor is there a clear vision of what is required or how to achieve it. It seems most wait for the Municipality or DWAF to act. In part, this seems to stem from a lack of clarity about the transfer of responsibility for water services from DWAF to the municipality, and the role of community members within this.

## HIV/AIDS prevalence and its social impacts

Public acknowledgement of HIV/AIDS dates back to 1990 in Wally, when people started getting sick. Many people here still do not talk openly about HIV/AIDS because of the extreme stigma attached to it. This has impacted harshly on families where one or more parents died, leaving children with no one to care for them.

In Mawa, HIV/AIDS has been acknowledged in the community since 1997, when a local NGO, Itereleng, starting running community education workshops. Prior to that people did not attribute deaths to AIDS, and there are still significant fears around the consequences of disclosure.

No reliable statistical data exist on the health status of these settlements; the information presented here is based on the views of local residents and clinic staff. Among adults, sexually transmitted infections (STIs), are the most common health problem, followed by TB (which is closely associated with HIV/AIDS) and diarrhoea. Amongst children, diarrhoea, colds and flu are the most common ailments.

There have been outbreaks of cholera, malaria and polio in the past, but apart from occasional cases of cholera, there have been no outbreaks for some time.

It was striking to note that more women than men in this area have disclosed their HIV positive status, as evidenced by their participation in support groups and focus group discussions for this research.

Few residents drew explicit links between HIV/AIDS and poverty. Some believe the pandemic is contributing to impoverishment, through the illness and death of bread-winners, expenditure on visits to the clinic and the marginalisation of orphans and vulnerable children. (Vulnerable children here refers to children with one or more ill parents.) Again, it was not possible to quantify the total number of orphaned and vulnerable children in the settlement. However, 33 orphans and vulnerable children from a community of 600 households presented themselves at a focus group discussion on this issue.

Living conditions are harsh for many orphans and vulnerable children. In some cases, relatives take care of them; some have to manage on their own, and rely on begging and whatever support the community provides. Most are referred to the Department of Social Development for food parcels, but they do not get cash grants and there are often delays in processing their applications for relief. As can be expected, their schooling suffers. Although most are still able to attend classes, some say they attend school not having washed or eaten for days. Most say they do not have time to do their homework and reading, as they have to take on household tasks after school.

Some children complained that their relatives or step-parents are cruel, making them work hard with little food or care. They have to fetch water when they return from school, often having to walk long distances. When the taps run dry, the return trip can take three hours. When they return, carrying 25 litre water containers, they are tired, and there are still more chores to do. They feel that the government has a responsibility to provide water to the community, since this was an election promise. Some children have to take care of their sick mothers or fathers. They said they find this very distressing at times.

Women fetching water, Mookgo

Home-based care volunteers are active in all villages. These are very committed individuals - mostly women - who take care of their fellow community-members who are elderly or ill. They assist them in fetching water, cleaning, washing and so on, and provide important emotional support.

## *Water and sanitation*

Water services differ from settlement to settlement, ranging from a reasonably well-functioning community borehole with public standpipes, to a complete breakdown in services.

**Mookgo**

*Water*

A regional bulk water scheme is in place, but has never been functional. Five boreholes have been drilled over the years, but only one provides water. A second borehole could supply water if the electricity meter, which was stolen, was replaced. The water supply from the sole functioning borehole is said to be erratic. Some days, water is available around the clock; at other times it provides water for three to four hours a day only, and sometimes delivers nothing for days. When it functions well, it provides 1.9 litres per second – enough for 80 litres per

**Orphans and vulnerable children**

Ananias is a 15 year old mentally retarded boy. His mother used to work before she died of AIDS. He does not go to school, but attends ABET (Adult Basis Education and Training) classes in his village. He does not wash regularly because there is no water, and does not eat properly since there is seldom enough to eat. He does not get much support from his step-mother and father.

person per day - which is a relatively high volume in the South African context. The water is slightly salty but this is perceived to be a significant problem.

The settlement is served by 22 public stand-pipes, but three of them are not functioning – probably because of pressure problems in the reticulation network. One section is not reticulated at all. Most taps do not have adequate drainage, and so there is a lot of grey water standing in the streets. The average time spent collecting water is half an hour a day, and respondents said the taps are too far away. Sick people find it difficult to walk the distance to fetch water. In this village men share the task of fetching water.

Man fetching water, Mookgo

Each household is required to pay R5 (0.63 €) a month for its water, and about half the households do not make this payment, citing poverty. Those who do not pay are encouraged to make some payment, however late, and are not prevented from collecting water. Money collected is used to pay the pump's electricity bill and replace stolen taps. There is no Free Basic Water, and residents are not aware of this policy.

Next to the public borehole is a privately owned borehole. When the community borehole fails, some residents purchase water here at R1 (0.13 €) for 25 litres. Others resort to raw river water, despite their reservations about its quality. Few boil the water they draw from the river. Despite problems in the continuity of supply, there appears to be enough water for productive purposes. Cattle owners have erected two concrete troughs for stock watering. Just under half of all the households have vegetable gardens, in which they grow spinach, tomatoes, cabbage, potatoes and papaya. The village and the gardens look green and well-watered. Brick making is also a common activity, which requires a lot of water.

*Sanitation*

An estimated 80% of residents have simple pit latrines, of which half are in good condition. The remainder use their neighbours' toilets, or relieve themselves 'in the bush'. Apart from 35 latrines built by the government for families most affected by floods in 2000, all toilets are built and paid for by the users themselves. When the pit is full, people save money to build a new toilet. Some people encounter problems with hard rocks and groundwater when digging the pits for the latrines, which limits their size.

Poor sanitation is a great concern in the context of HIV/AIDS. One person said, "People that are infected sometimes have diarrhoea and then do their necessities in the bush, just where our chickens eat". However, no explicit links were drawn around the broader health risks posed by inadequate sanitation, or the particularly susceptibility of HIV positive people to infections and diseases.

**Mawa**

*Water*

Water supplies in this settlement are highly problematic. There is a borehole, but it does not function since the electricity supply for the pump has been cut off. This followed an announcement by ward councillors that water should be provided for free, in line with the national free basic water policy. Unfortunately the municipality had made no provision for Free Basic Water services. Residents stopped paying their R6 (0.75 €) monthly contribution, and after several months of non-payment by residents, the electricity supply was cut off, leaving the settlement with a debt and no water service. The CCC has approached DWAF and the municipality to intervene, but to no avail.

Previously, households were served by yard taps, and water collection took five minutes. Residents now rely on water collected from holes dug in a (seasonal) dry river bed, where the water quality is said to be poor.

Fetching water from pits in the river bed, Mawa

This task now takes up to three hours a day, factoring in the walking distance and the time taken to scoop water from one metre deep holes in the sandy river bed. This task falls predominantly on women and children, as less than 10% of men were said to help collect water. In the case of child-headed households, it is the children who have to fetch water from the river. Those who are ill rely on their children or relatives to collect water, as home-based care volunteers seldom have the time to collect water for them in addition to other support activities.

Women and girls have been raped when walking to the river bed to collect water. Others have had goods stolen from their homes when they were out fetching water.

Previously, most households had food gardens, but their gardens have died in the dry season since the water supply was cut off. Some home-based care volunteers were growing vegetables – carrots, beetroot and spinach – to supplement the diets of those they were caring for, but their gardens have also died since their water supply was cut off. Most families have livestock which need water.

Despite these problems, informants said the main development priorities for the settlements are the establishment of a clinic, a tarred road, a police station and an improved water supply - in that order. They see the main impediments to achieving these goals as the lack of co-operation between different stakeholders within the community.

*Sanitation*

An estimated 90% of households have a simple pit toilet, although many are in poor condition. The remainder ‘use the bush’ or share the toilet of a neighbour or relative. Significantly, participants in focus groups in this settlement identified toilets, along with good food and clean households, as being important factors in keeping HIV positive people healthy.

**Wally**

*Water*

In the early days of the settlement, established in 1968, people drew their water from springs and a nearby river. In 1984 the then Lebowa ‘homeland’ government installed standpipes, supplied with water from the nearby Letaba River via an electric pump.

**Collecting water when you are sick**

Maria is too ill and weak to do hard work. Her children fetch water for the family when they return from school. They used to pay R5 a month for water from the standpipe, but can no longer afford to pay. When there is no water at the standpipe, she borrows money from her neighbours and buys it from a private borehole at 50 cents per 25 litres – which is more expensive.
Maria started a food garden, but is now to weak to work in it.
She does not have a toilet, but uses her neighbour's when she is pressed. At other times she uses the bush. She would like to have her own toilet as this would make things easier for her.

Residents say they cannot afford the monthly water tariff because of high unemployment, and have stopped paying. As a result the water pump's electricity supply has been cut-off. As in Mawa, residents now rely on seep holes dug in a nearby dry river bed, and share their water supply with local livestock. Again, the task of collecting water falls predominantly on women and children.

The community is fragmented, and local structures seem to have largely disintegrated. There is little evidence of any concerted local action to address these water problems.

The impact on those infected and affected by HIV/AIDS is harsh. Those who are ill are frequently too weak to collect water themselves must rely on relatives. The time taken to collect water for themselves erodes the time available to care-givers to provide support and assistance. Limited water also impacts on food gardening, essential for supplementing the diets of those who are HIV positive, and production of vegetables for sale.

*Sanitation*
Most households have their own toilets, although most are in poor condition. A government programme provided a small number of VIP toilets in 2000, but far more are needed. Residents say they do not know how to access support.

## Impacts on different groups in the community

In the context of HIV/AIDS in the villages, the implications of poor water and sanitation services are different for men, women and children. Women take primary responsibility for most household tasks, including fetching water, with support from children. Although clear statistics are not available for the villages in the case study, anecdotal local evidence suggests that HIV/AIDS prevalence is slightly higher among women than men. In households affected by HIV / AIDS, women and children feel the implications of poor services particularly harshly, as it adds to the burden of care and the work of maintaining a household.

## Health and hygiene awareness

Informants repeatedly identified good food and exercise as important ways of maintaining the health of people living with AIDS, and saw availability of water as essential for food gardening to grow vegetables and fruit.

None drew any direct linkages between the health of HIV positive people or those with AIDS and the quality and availability of water and sanitation. Drinking raw river water is seen as a potential risk for cholera infection, but there was little awareness of the particular vulnerability of HIV positive people to infections and diseases stemming from poor quality or inadequate water and bad sanitation. There was no evident awareness of the importance of cleaning water containers regularly, or regular hand-washing – although difficulties in collecting water for domestic use is a powerful disincentive for frequent hand-washing.

Even health education messages provided by clinic nurses neglected these linkages. Nurses provide general information prevention and treatment of various diseases, such as TB, diarrhoea and HIV/AIDS, through discussion and materials such as posters in the different local languages. There is no integration, though, between the different information programmes – between water, sanitation and AIDS care, between TB and AIDS, and so on.

General HIV/AIDS education and awareness raising is undertaken by nurses, home-based care volunteers, the Itelereng Education Programme, other NGOs and local youth groups. Their activities include drama, poetry, conventional education and discussions. Their main focus is on prevention of HIV/AIDS and on health maintenance for those who are infected, relying primarily on promotion of healthy food. They also promote regular clinic visits and information on how to access food parcels provided by the Department of Social Development.

In Mookgo, a youth group presents dramas and poems which contain messages around HIV/AIDS prevention. It does not address care, support and treatment of those who are HIV positive, although they recognise this would be an important area to work in. They feel there is considerable stigmatisation of those who are infected, and that messages around caring for the ill would not go down well. Some youth group members provide care and support to orphans and those who are ill.

A further area of health and hygiene education is through ABET (Adult Basic Education and Training) courses.

### *Water for food production and other productive uses*

Awareness of the importance of good nutrition has been a powerful spur to food gardening, but problems with the availability of water are compromising efforts to maintain viable gardens. Arguably, there is considerable scope for education campaigns around re-use of grey water and rain-water harvesting. This is, of course, taxing for those who are ill, and obliges them to rely on the assistance of others.

There is no clear institutional response to small-scale vegetable gardening initiatives, even outside of the context of HIV/AIDS. The co-ordinator of GTMAC acknowledged that it would require a co-ordinated effort by the Department of Agriculture, DWAF and community members to further promote and support such initiatives, because at present there are no formal programmes to support small-scale vegetable gardening for those infected and affected by HIV/AIDS.

Vegetable garden, Mookgo

## Section 4: Conclusions and recommendations

### *Conclusions*

*Taboo and stigma*

For many South Africans, open discussion of HIV/AIDS remains taboo. This has major implications for research methodologies in related areas. It is necessary to work with people and groupings in the community who have moved beyond concerns around disclosure and stigmatisation, and even so, HIV/AIDS-related issues must be approached with extreme sensitivity. This highlights the importance of programmes which seek to ‘break the silence’, and build support for those who disclose their status.

*Service provision*

To date, most South Africa policy initiatives have focused on the prevention of HIV/AIDS, rather than treatment, care and support of those infected and affected by the virus. Those that do engage with the

challenges of living with the virus concentrate largely on its health dimensions, through the establishment of and support to home-based care groups, voluntary counselling and testing and provision of food parcels. Although poverty alleviation and provision of good public services are identified in the national HIV/AIDS policy as key strategic areas, there is a long way to go still in delivering tangible outcomes. In the study area, a start has been made with the involvement of the Department of Agriculture in local HIV/AIDS initiatives, but DWAF itself remains outside these.

Public services, including sealed roads, clinics, water supply and sanitation, remain deficient in many rural areas in South Africa. Historical inequities are the major reason for this, but even where water services have been improved recently, there are significant problems with sustaining reliable services.

Significant factors here are limited participation by local residents in decision-making, operation and maintenance of water services, and relatively weak community structures. This impacts particularly harshly on those living with HIV/AIDS, as they seldom voice their service needs publicly, and their particular difficulties are not yet acknowledged or addressed adequately by those responsible for local service provision. This is compounded by the reality that there is a widespread expectation that government will attend to community needs, with little local initiative required. One implication is that government agencies need to be considerably more pro-active in monitoring the implementation of national policies.

A second area of concern around sustainable servicing relates to payment for water. Although water tariffs are modest, many residents do not pay for water when required - even where acute poverty is not the primary constraint. Municipalities must phase in Free Basic Water by 2005, but it will be some time before the benefits of this policy reach the rural poor who need it most. In the interim, service payments must continue if service failures are to be avoided. The reality is that the cost to residents of a basic water service is far less than the cost of other goods and services. Indeed, the non-monetary cost of a service breakdown is extremely high, particularly for those who must now spend time fetching water from unprotected sources. Arguably, these non-monetary costs are far higher than the cash value of the service tariff.

### *Impacts of poor services*

Poor water services impact across the board, but their impacts are particularly severe for the elderly, children, and those who are sick or weak. In communities where people have reverted to collecting river water, those who are ill frequently do not have the strength to fetch water and must rely on the kindness of relatives – including children – or friends. Time spent fetching water also erodes the time available to home-based care volunteers to care for the sick. In many instances, those who are ill or weak are obliged to buy water from those with private boreholes, at a higher cost.

For women and girls, collecting water from the river presents a risk of rape – and may expose them to HIV infection.

Good sanitation is essential for dignity, well-being and public health, but is particularly important for those whose compromised immune systems make them more susceptible to diseases and infections spread through exposure to sanitation-related pathogens. Frequent diarrhoea is one of the grimmer realities of advanced AIDS, and those who are ill and weak need ready access to safe and congenial facilities. Equally, the burden of care is eased when toilet facilities and water for washing and drinking are accessible close by.

## Health and hygiene

Eating healthy food, such as fruits and vegetables, are considered the most important way to stay healthy for persons that are infected. These are often expensive and hard to come by where they are not produced locally. Where water is readily available, many families have vegetable gardens; when water supplies fail, the impacts are felt far beyond domestic consumption, as food gardens die and livestock suffer during the dry season without water.

Health and hygiene education is provided in various ways. There is little water and sanitation content, and HIV/AIDS material focuses predominantly on prevention, rather than treatment and care. The

main message for those living with the virus is the importance of healthy food and exercises – with little promotion of basic hygiene, water care and good sanitation. This highlights the fragmentation of health and hygiene education programmes.

## Recommendations

### *Policy regulation and support*

In its capacity as water sector regulator, DWAF must become far more pro-active in monitoring the provision of basic water services and providing active support to address service failures – not least because of the consequences of inadequate services or service failures for those infected or affected by HIV/ AIDS.

References to HIV / AIDS in the Strategic Framework on Water Services need to be translated into active programmes of strategy development with, and support to, municipal authorities. But the starting point must be a comprehensive programme of sensitisation and training within DWAF itself. Without this, DWAF staff themselves will continue to have a limited understanding of the role effective water services play in supporting the health of those who are HIV positive, and will remain poorly equipped to provide support and guidance to service providers and colleagues working in related sectors. DWAF leadership must be seen to be driving this.

### *Water for productive purposes*

Provision of water for productive purposes needs to be given far higher priority by policy makers and service providers. This raises complex issues around what level of basic water supply is needed to promote sustainable livelihoods, and how to allocate and cost water for productive as opposed to domestic purposes. Nonetheless, the need for clear national and local strategies to address this is now urgent.

### *Co-ordination between DWAF and Agriculture*

Food gardening for nutritional supplementation is likely to become even more important as the number of AIDS-sick people rises. This will require close interaction between DWAF and the Department of Agriculture to develop appropriate programmes and support measures. These should address the provision of information on basic food gardening, appropriate technologies for water delivery, promotion of rain-water harvesting and grey water recycling, and seed distribution systems. Extension programmes must focus more directly on subsistence production and basic household nutrition.

### *Integrated health and hygiene education*

Health and hygiene education initiatives need to be integrated better to promote awareness of the close linkages between water, sanitation, hygiene and health, and, in particular, their importance in maintaining the health of those who are HIV positive. This requires close co-ordination between municipal and provincial health authorities and with DWAF, agreement on the core content of training programmes and information campaigns, and alignment of programmes run by different agencies.

DWAF-funded water and sanitation programmes are currently required to address integrated health and hygiene promotion, but they need to be strengthened considerably if they are to have any practical impacts. In addition, this approach needs to be extended to water sector infrastructure programmes not funded by DWAF, through close co-ordination with municipal and provincial Health authorities and active lobbying by DWAF. Civil society organisations have a huge role to play in supporting these programmes, not least by facilitating linkages on the ground to stitch together the silo-ed approaches of difference government programmes.

School water and sanitation has been neglected badly in the sector. Enormous backlogs and service failures exist, particularly in rural areas. Interventions need to make full use of the opportunities provided in the school curriculum for integrated health and life skills education, and to link this with information around good sanitation, water care and HIV / AIDS. To date very little has been done to highlight these linkages or implement effective programmes, let alone equip learners with the knowledge needed to safe-guard their own health and that of HIV positive family members or friends.

Substantial resources have been earmarked to support the roll-out of anti-retroviral treatment programmes. Training of home-based care givers and health personnel is a vital component of this programme, and DWAF must be pro-active in ensuring that the training content provides relevant and practical information on linkages between water, sanitation and hygiene and HIV / AIDS.

### *Role of local structures*

Finally, creative thinking is needed to redefine the role of community-based structures in the new context of municipal service delivery. Municipalities have a leading role to play in supporting local development, but this cannot be at the cost of local initiative.

Local residents and their organisations have a critical role to play, not only in planning and supporting effective operation and maintenance of water services, but in driving local AIDS awareness, prevention and support initiatives. Equally, local structures that promote accountability by service providers can play a decisive role in mitigating some of the impacts of HIV / AIDS and building more 'AIDS competent' communities.

Despite the poverty and hardship we witnessed in the course of this research, there is an immense reservoir of goodwill, experience and positive thinking in these settlements that must be mobilised if the needs of the poor are to be addressed, sustainably and effectively. In a context of widespread HIV/AIDS, this is critical.

"The Mvula Trust is now revising its own project implementation approaches and strategic objectives to ensure these issues are addressed more effectively in our own practice."

## *References*

Barnett, T. and A. Whiteside (2002) *AIDS in the Twenty-First Century; Disease and Globalization.* Palgrave publishers, Hampshire, United Kingdom

Butterworth, J.A., Moriarty, P.B., & van Koppen, B. (2003). *Water, poverty, and productive uses of water at the household level: practical experiences, new research, and policy implications from innovative approaches to the provision and use of household water supplies*. Proceedings of an international symposium held in Johannesburg, South Africa, 21-23 January 2003.

Department of Health (2000) *HIV/AIDS/STD Strategic Plan for South Africa 2000-2005*. Pretoria, South Africa

Department of Health (2003) *Tracking Progress on the HIV/AIDS and STI Strategic Plan for South Africa*. Pretoria, South Africa.

Department of Water Affairs and Forestry (2003) *Strategic Framework for Water Services; Water is Life, Sanitation is Dignity*. Pretoria, South Africa

HSRC (2002) *Nelson Mandela/HSRC Study of HIV/AIDS*. Humans Sciences Research Council Publishers, Cape Town, South Africa

Kamminga, E. and M. Wegelin-Schuringa (2003) *HIV/AIDS and water, sanitation and hygiene*. Thematic Overview Paper, IRC International Water and Sanitation Centre, Delft, the Netherlands

Moriarty, P.B. & Butterworth, J.A. 2003. *The productive use of domestic water supplies: how water supplies can play a wider role in livelihood improvement and poverty reduction*. IRC Thematic

Overview Paper, IRC International Water and Sanitation Centre, Delft, The Netherlands. Available at: http://www.irc.nl/page.php/256

UNAIDS (2002a) *AIDS epidemic update*. UNAIDS-WHO.

UNAIDS (2002b) Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections: South Africa. UNAIDS – WHO – UNICEF.