



**MARKETISATION OF
MUNICIPAL SERVICES,
DAILY LIFE AND HIV
IN SOUTH AFRICA**

A Grahamstown case study

Municipal Services Project

Occasional Papers No.14



Occasional Papers Series
Number 14

MAY 2007

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A Grahamstown case study

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ABOUT THE PROJECT

The Municipal Services Project (MSP) is a multi-partner research, policy and educational initiative examining the restructuring of municipal services in South(ern) Africa. The Project's central research interests are the impacts of decentralisation, privatisation, cost recovery and community participation on the delivery of basic services to the rural and urban poor, and how these reforms impact on public, industrial and mental health.

The research has a participatory and capacity building focus in that it involves graduate students, labour groups, NGOs and community organisations in data gathering and analysis. The research also introduces critical methodologies such as 'public goods' assessments into more conventional cost-benefit analyses.

Research results are disseminated in the form of an occasional papers series, a project newsletter, academic articles/books, popular media, television documentaries and the internet.

Research partners are the International Labour Research and Information Group (Cape Town), Queen's University (Canada), Rhodes University (South Africa), the Human Sciences Research Council (Durban), EQUINET (Harare), the South African Municipal Workers Union, and the Canadian Union of Public Employees. The Project is funded by the International Development Research Centre (IDRC) of Canada. For more information visit www.queensu.ca/msp.

ISBN 978-0-86810-440-9

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Design and layout: Joe Goosen

Printed and bound by Logo Printers

Acknowledgements

We would like to express our appreciation to those individuals and families who agreed to be interviewed for purposes of this research and that welcomed us into their homes.

We also appreciate the co-operation of municipal officials who made information available and agreed to be interviewed. Thanks to David MacDonald, Greg Ruiters and Cathy O'Shea for feedback and editing.

Photographs by Pumla Ntlabati and Kevin Kelly.

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SUMMARY

In this study we are concerned with understanding the impact of basic municipal services on the treatment, care and support of people sick with HIV-related illnesses. In particular, we enquire into the 'marketisation' of basic services and the implications this might have in the lives of those caring for people living with AIDS. Marketisation refers to policies and practices that present municipal services as economic goods or commodities, not as entitlements. Marketisation does not exclude life-line water supply. What it means is that any amount of water used over this minimum 'life-line' amount are charged at market-related rates, i.e. on a cost recovery basis.

The study was conducted in an Eastern Cape town, and is based on interviews and home visits to 30 households where one or more family members is being cared for with HIV-related illnesses. The research focuses on the use of electricity, water, sanitation and refuse removal facilities in caring for those sick with AIDS. General household living conditions are also considered in understanding the challenges of AIDS care.

Our findings were that most families have only occasional access to limited supplies of electricity and municipal water allowances - far less than is required for washing and caring for the sick. Most households have access to water from a yard tap only, and no run-off to dispose of waste water from washing. They also have limited access to electricity and need to burn wood and paraffin for heating and cooking in homes without ventilation. The difficulties of caring for the sick without basic facilities are made worse by the crowded conditions in homes.

Only 44% of respondents were not in arrears of payments for basic services to the municipality. Most (56%) of households have arrears for basic services at the level of about 5 to 10 times their monthly household income, and they are not able to 'normalise' their access to paid services without having to pay off arrears. The average amount owed was R7 150. An untenable situation exists with no apparent solutions in sight as the municipality tries to recoup its R100-million debt by various strategies that they do not apply consistently, and which community members often do not understand.

Almost all households in the study area depend on various social assistance grants.

The study shows that AIDS care increases the demand for electricity and water. Without them, people with AIDS are less able to care for themselves

and household members are less able to care for them when they are bedridden. The sanitation situation is dire, both in terms of disposal of waste water and toilet facilities, and poses a serious health risk to HIV positive people and their families. There seems little chance that HIV-affected families will ever be able to meet their basic health needs without some form of further help in a situation where water is cut off and restricted after non-payment and free basic electricity is only accessible on successful application for concessions. Such applications are in most cases are unsuccessful because if families receive grants they are often not eligible for concessions. Significant inefficiencies and lack of clarity about allowances are further obstacles to service access.

Most households spend 10% of the total household income on electricity. Ninety percent of such households cannot or do not pay for usage above six kilolitres and most are placed on restricted flow systems. There is a clear need to raise the concerns highlighted in this study to the forefront of AIDS care advocacy.

INTRODUCTION

The consequences of AIDS for households in South Africa have been well documented.¹ We know, for example, that families affected by AIDS have higher health care costs, face extraordinary transport expenses and other costs, divert income to AIDS care from other sources, often experience loss of income and fixed assets, have higher levels of borrowing, and experience high burdens of care and associated loss of productivity. In addition, they are often stigmatised and have to deal with profound psycho-social changes related to illness and death of family members.

AIDS treatment, care and support have largely been about specific professional services² to individuals and families in need. But we need to take into account the context in which people are sick, and care for the sick, when we develop treatment and care services. In this research we are concerned with understanding the impact of government strategies in South Africa for provision of basic municipal services and what this means for households managing AIDS-related illnesses.

There has been surprisingly little research on the impact of marketisation³ of basic services on the ability of poor people to cope with illness and particularly with HIV-related illnesses. There is evidence⁴ to suggest that the health of people sick with AIDS, and their communities, is compromised by lack of sufficient and clean water for sanitation, washing, drinking and caring. Recent research has noted that the water sector should pay closer attention to the effects of inadequate services with those who are HIV-positive,⁵ and to the need for reliable water supply and sanitation for homecare.⁶ But there does not appear to be any research which has specifically considered the link between marketisation of basic services and the health care of HIV-positive people.

Marketisation of urban services refers to a broad movement that insists that water and urban services are most efficiently used when they are regarded as economic goods or commodities, not as entitlements. Marketisation does not exclude life-line water supply. What it means is that any amounts in excess of life-line are charged at market related rates, i.e. on a cost recovery basis, and that households may therefore have intermittent access.

Marketisation of basic services in South Africa has been accepted as a national strategy for service provision. There is simmering tension about the strategy, including its constitutionality, but there has not been a great deal of research on its consequences. Therefore, this study also aims to understand how the topic should be further researched.

We have set out to examine whether the strategies for provision of basic services have any impact on the quality of AIDS care. In particular we enquire into the ‘marketisation’ of basic services and the implications this may have on the lives of those caring for people living with AIDS.

The geographical study area was chosen so that we could cover a range of types of service provision. These included: 1) no stand water, no electricity, no refuse removal and no sanitation services; 2) pay-card electricity and stand water available through a yard tap; and 3) pay-card electricity and restricted water in the household.

A secondary focus is to explore the claim that “Marginalized socioeconomic groups... tend to have only a weak capability to cope with the consequences of HIV/AIDS related illnesses and death”,⁷ but there has been little empirical study of this. Little is known about the survival strategies of families directly affected by AIDS-related illness. In this study we are concerned with understanding the impact of living conditions on the treatment, care and support of people sick with HIV-related diseases and how individuals and family cope with this.

OBJECTIVES AND SCOPE OF STUDY

The objective of the research is to assess the impact of municipal service delivery on households coping with HIV/AIDS. This includes water, electricity, sanitation and waste management services. The research examines the impact of different types of basic services on HIV/AIDS.

The key questions which the researchers set out to address were:

- What is the impact of marketisation of basic services on the ability of persons with HIV, and other members of their households, to cope with HIV-related illness?
- How does the stigma associated with HIV/AIDS affect the ability of households and communities to cope with the illness and mobilise for needed resources, including access to specific basic services?
- Can a broader study asking the same questions yield quantitative comparisons of health status indicators for persons with AIDS, and members of their households, exposed and not exposed to marketisation of basic services?

METHODOLOGY

Approach

The study was conceived as an exploratory study. We did not draw up hypotheses from the beginning. Instead, we set out to identify lines of enquiry that would be fruitful to pursue in a larger study and in more depth.

The site studied was chosen for convenience, largely because the researchers are well acquainted with the area, have done previous research on HIV issues in the town, and they had established good local contacts and support as a foundation for the study.

Scoping

The following preparatory steps were undertaken:

- *Interviews were conducted with five key officials involved in the provision of services to understand the municipality's approach to basic service provision. We took handwritten notes during these interviews and collected documents related to service delivery for each of the basic services.*
- *A focus group discussion was conducted with eight homecare providers who visit sick people and support families in caring for them. Five were local volunteers attached to primary health care clinics in the study area, and three others worked for the local hospice association, which also provides direct services to families as well as training for homecarers. The focus group discussion was audio-taped, translated and transcribed. The transcript was coded using qualitative data analysis software. The primary codes used in the analysis were: care needs of families; how these evolve over time; specific care needs related to each of the basic service categories; and a number of minor codes. The coded material was collated and used to formulate questions to be asked in a structured questionnaire administered to AIDS-affected households*

Questionnaire design

For the survey component, a structured questionnaire was designed to obtain factual information about such facts as household income and size, HIV/AIDS and other illnesses in the family, service access history, and employment history.

The questionnaire also included questions designed to obtain information about the experience of living with AIDS and caring for someone with AIDS, with specific reference to availability of basic services and the impact of service access on ability to manage HIV/AIDS.

The questionnaire also included a 'household tour' observation protocol for gathering information about household living arrangements and basic services access, especially regarding management of illness.

The questionnaire was translated into Xhosa and piloted in two households not affected by AIDS, but familiar with families caring for AIDS-sick individuals.

Survey sampling and recruitment

Identification of 30 households was done through local home-based care supporters contacted through an AIDS support organisation and local clinics.

The geographical area was chosen so that a range of types of service provision would be covered. These included: 1) no stand water, no electricity, no refuse removal and no sanitation services; 2) pay-card electricity and stand water available through a yard tap; and 3) pay-card electricity and restricted water in the household. These represent the three 'types' of service access in the area of the town which has almost all of the known cases of people being cared for at home with HIV-related illnesses.

Homecarers were requested to ask people to whom they provided homecare assistance if they might be prepared to participate in the study. They were instructed in how to explain the study to potential respondents and to ask if they would be willing to be approached by the researchers. The homecarers needed to discuss participation both with the person most involved in illness care within the home, and with the sick person/s. If respondents did not mind being approached by the research team, they were informed that on the next visit the homecarers would be accompanied by a field researcher who would discuss the possibility of participation and answer any questions about the research. Researchers told householders that they did not have to participate and that they could withdraw if they didn't want to speak to the researcher when he/she visited.

In most cases during the first visit by the researcher, after consent was established, the respondents were willing to conduct an interview immediately. In other cases a return visit was arranged. Participants were without exception prepared to participate and they signed consent forms after hearing an explanation of what would be required of them.

Interviews were also conducted with neighbouring households not affected by AIDS, to compare results with AIDS-affected households. We also hoped to establish an understanding of stigma related to AIDS and its possible impact on community solidarity around AIDS care and especially resource sharing with respect to basic municipal services. Six households not affected by AIDS were selected, with two households representing each of the three service profiles.

Survey data gathering

On average, household visits lasted about one hour.

Most household interviews were conducted in isiXhosa, as 93% of the households had this as their home-language. The remaining 7% of interviews were conducted in English although the home-language of respondents was Afrikaans. This was because the researchers did not speak Afrikaans and the respondents were fluent English speakers.

Each household visit comprised three parts:

- A structured questionnaire interview conducted with the person in the household most involved in care of sick people, but who needed to be a senior member of the household with access to information related to service payments.
- The researchers then requested respondents to show them around the house to better understand 'how things work' with respect to basic services usage and AIDS care. The researcher recorded details of the house tour using a field-note recording form organised into categories of information.
- Semi-structured interviews were conducted with an HIV-positive member of the household and a person playing a caregiver role, singly (15 minutes each), or together where appropriate.

Researchers wrote down the answers given.

Further in-depth interviews

The quality of information in the interviews on issues of AIDS care yielded poor information. We therefore decided to supplement this part of the study with five more in-depth interviews. The cases were selected according to a subjective estimation of which respondents were most likely to provide detailed responses to questions. The interviewers also aimed to capture a range of experiences across the three different sites. In some cases the interviews were with carers, but on three occasions also included the person sick with AIDS. The interviews were designed to obtain information about the experience of living with HIV and caring for someone with AIDS, and specifically about the availability of basic services and the impact of service access on ability to manage HIV/AIDS.

These interviews were translated and simultaneously transcribed from Xhosa to English and coded using similar categories to those used in the focus group discussion.

Ethics

The research proposal was reviewed and approved by the Rhodes University Ethical Standards Committee.

A low risk for negative repercussions was anticipated, since the study was conducted in households that had already been visited by home-based care supporter and the household members were only visited after hearing an explanation of the study's purpose.

Participants were asked to sign a declaration stating that they agreed to participate in the study, that they understood the purposes of the study, and that they knew they could withdraw at any point. After the interviews the head of the household was presented with a R50 supermarket voucher to thank him or her.

In-depth interview respondents

- A 41-year-old woman living in an informal settlement. Both she and her husband are HIV-positive, unemployed and living by themselves. The husband is the main caregiver, and is epileptic.
- A 73-year-old woman looking after a 3-year-old HIV-positive grandchild. She had previously nursed a daughter until she died of AIDS (not the 3-year-old's mother). She lives in an informal settlement with no services.
- A middle-aged women recently diagnosed HIV positive and who is not accepted by her family. She is unemployed, has three children, and her partner has not been tested. She has recently moved into her RDP house in a new settlement area. The interview was conducted with the respondent and her daughter.
- A 26-year-old woman who is semi-paralysed and is in a wheelchair, and her mother, who is the main caregiver. The patient is reported to have been paralysed after being diagnosed with HIV. The main respondent is the patient's mother.
- A family of five depending on the grandmother's (caregiver) pension and one child support grant. The interview was conducted with the sick person, a woman in her 30s who is in a wheelchair, and her mother, who is the main caregiver.

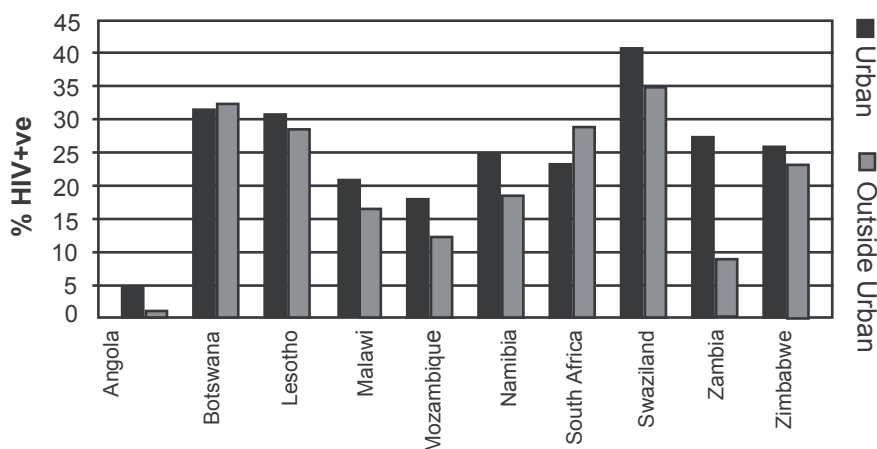
RESEARCH CONTEXT

HIV and urbanisation

There is a well established relationship between urbanisation and HIV prevalence in Africa. A 2005 review of pregnant women across the continent shows 1.7 times greater median value HIV prevalence in urban areas (Garcia-Calleja et al., 2006).

The following figure illustrates the differences between urban and rural antenatal HIV prevalence in ten Southern African countries.

Figure 1: Urban and rural HIV prevalence in Southern African countries



Comparison of rural vs. urban HIV prevalence using antenatal clinic data from 10 Southern African countries (last year for which data was available before 2004) Data source: chart constructed from data reported in Asamoah-Odei et al., 2004.

In all countries, apart from South Africa and Botswana, there is a higher HIV rate in urban areas. The different situation in these two countries is possibly due to stronger labour migration patterns, but it has not been satisfactorily explained. The general finding is that HIV has spread more rapidly in urban areas.

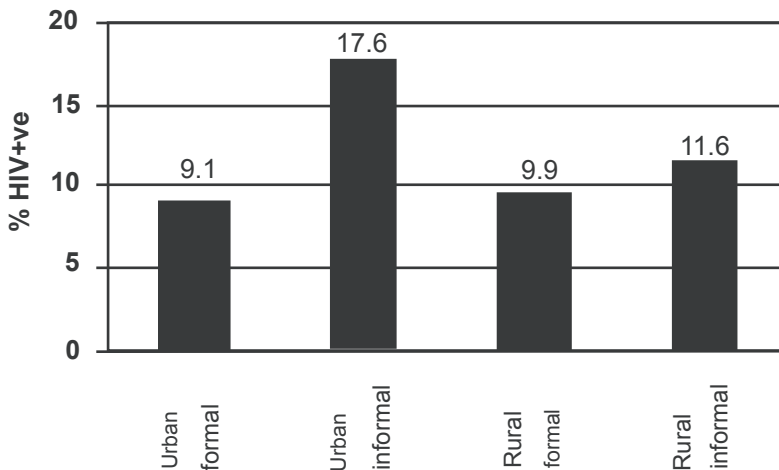
There is strong evidence from South Africa that urban prevalence is much higher in urban informal settlements⁸ than other settlement types. These are often associated with movement of people from rural to urban

areas. By “urban informal settlements” we mean temporary settlements which do not meet with municipal approval and which are not currently included within municipal development plans. They do not have stand number and municipalities are reluctant to provide services when they want these communities to settle elsewhere.

“Among the factors helping drive the spread of HIV is the combination of unequal socio-economic development and high population mobility...The epidemic is worsening and is concentrated chiefly among socially marginalized populations.”⁹

The following figure represents the national picture of HIV prevalence in South Africa by settlement type:

Figure 2: HIV prevalence in SA by settlement type

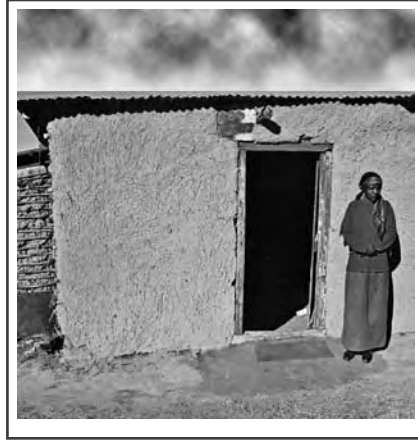


HIV prevalence among persons aged 15-49 years by settlement type, South Africa 2005¹⁰

This means that we can expect a higher burden of AIDS in informal housing in the cities. This is also the housing type with poorest access to basic services.

To understand high prevalence in informal urban areas we need to examine the social conditions in situations of rapid urbanisation. Unfortunately this is an under-researched area. Most of the research on the social aspects of AIDS has focused on individuals and their behaviour. Consequently we have only a basic understanding of the relationship between community living conditions and HIV prevalence.

The town



Strong contrasts between a well developed and economically active centre, and a marginalised, poverty stricken periphery with no municipal services.

Grahamstown is a small in-land town located in Makana Municipality in the Eastern Cape Province of South Africa, mid-way between the cities of Port Elizabeth and East London. The larger municipality has a estimated population of between 74 000 to 120 000, but the town itself has about 62 000 people.

It comprises a town centre, which is dominated by a business district and university close to well-established suburban settlements, and an urban black¹¹ township area stretching over two or so kilometres. This section is often referred to as Grahamstown East.

Grahamstown dates to the early 1800s and its townships are well-established. Although some of the housing in the Rhini and Fingo Village areas was built recently under the present government, other buildings date back more than 50 years. Marked by a stream, which historically separated the predominantly black population from the white, there is a deep poverty-divide between the East and West of Grahamstown. This divide persists in the post-Apartheid era. Grahamstown East is marked by lack of commercial development, small houses, pot-holed roads and relative lack of street lighting. By comparison Grahamstown West has gracious colonial buildings, treed suburbs, a growing commercial centre, and excellent urban infrastructure.

The population of Grahamstown is 90% black and 10% white.¹² Grahamstown has very pronounced social divisions. People still live, divided by 'race', in distinct, separate areas. The study was conducted in the 'black townships'.

According to the 2001 census 27% of Grahamstown residents (aged 15-65) are employed. Thirty-four percent describe themselves as unemployed or unable to find work.

The HIV/AIDS context

HIV prevalence (adults 15-49 years) for the Eastern Cape was estimated at 15.5% in 2005.¹³ No reliable HIV and AIDS prevalence data is available for the municipal area, but based on collation of data from a number of sources, we estimate that the population prevalence in the municipality is around 11%. HIV prevalence among 15- to 19-year-olds using public sector clinics has been estimated at 17%. Although no official statistics exist on the geographical spread of HIV in the area, the overwhelming majority of those accessing HIV support services are from Grahamstown East.

It is estimated that there are approximately 8 000 HIV-positive people in Makana Municipality, with at least 800 of them in stage 3-4 of HIV/AIDS progression. There are believed to be at least 700 orphaned children¹⁴ in Makana Municipality, most of whom have lost either a mother or both parents as a result of AIDS. More than 80% of these are likely to come from Grahamstown.

Responses to HIV/AIDS

A survey of HIV-related activities in Grahamstown¹⁵ conducted in 2003-2004 identified 67 different organisations involved with AIDS response. These include 30 different NGOs, CBOs and FBOs. More than 600 volunteers were affiliated with these efforts.

Some of the major organisations include the Grahamstown Hospice; the Grahamstown Health Forum, which oversees a network of 45 clinic-based caregivers; and the Raphael Centre, which provides VCT, counselling, and education, as well as support to vulnerable children. Funding to support these efforts comes from government sources, private foundations and international development agencies, and local businesses. The ART programme at Grahamstown's Settlers Hospital is reputed to be one of the most well developed and managed in the province. In January 2007, 850 patients were enrolled in the programme. There is no waiting list.

The area of Grahamstown covered in the study

The two areas of Grahamstown covered in this research are Rhini and Fingo village, which have a combined population of about 40 000. The population of the area has not changed much recently, although some¹⁶ farm workers have come to the town in the past few years as a result of the development of game farming locally.



Community AIDS meeting

CONTEXTS OF AIDS CARE

The following findings are based on an analysis of the survey.

Household composition

The average number of persons per participating household is 5.5 and the range is from one to 13 people in a household. Mostly the households are occupied by family members living together, often with extended family members and their partners.

The average number of children under 18 per household is 2.1 and the range is from no children (17% of households) to seven children.

In 57% of the households the highest educational qualification is grade 11 or less.

Dwelling

"I had a case of a young HIV- positive child and what really wrenched my heart was to see how bad it became when it is raining. It's a mud house and everything gets soaked through, including the bed. The house practically falls apart. They were promised waterproof sheeting but this hasn't been provided yet. I dread to think of what will happen if it starts raining again. I think even if they are not given proper houses it could be ensured that they are at least covered against the elements and the like. I mean take care of their basic needs, including basic services." (Homecarer)

The houses of those who took part in the research were generally extremely cramped and small. The average number of sleeping rooms in a house is 1.8, meaning that an average of 3.3 people sleep in a room, and half of the houses have only one room for sleeping. In 60% of households the living room is used for sleeping.

About half (48%) of the houses do not have a kitchen area separate from the living room. None of the houses have a separate room for bathing. Only 11% of households have an inside toilet (more is said about sanitation below).

Most of the houses (83%) are owned by a member of the household. The majority of house (67%) are constructed of brick or concrete, while 33% live in self-built houses made of stone, mud, wood or metal sheeting. 20% of households are part of an informal settlement which is not municipality approved or serviced.

The dwellings are generally not weather-proof, and 66% of households report getting moderately to severely damp during rain. Fifty four percent of households have no insulation or form of heating in the home. The other 46% are able to burn paraffin or a brazier in the home, for warmth.

Sources of income

For 73% of households the main sources of household income is one or more government grants. 79% of households receive some form of grant or pension. This indicates a much higher reliance on government grants than was found (10%) for HIV-positive people in a national population-wide HIV prevalence survey conducted two years earlier.¹⁷

Respondent: *I have recently received a grant, but before that we used to live on R250 for my child's maintenance. We had to have food, clothing and all our needs had to be covered by that R250.*

Interviewer: *When did it start and how much is it?*

Respondent: *I first got it in March.*

Interviewer: *Is that the disability grant because of your HIV status? (Yes.) And you were diagnosed this year... does it come out so soon?*

Respondent: *Yes, it was quick, the application was made through the clinic in November and I got it in March.*

Interviewer: *How much is it?*

Respondent: *It was R720, but it has gone up to R820 now, since April.*

Interviewer: *And now that you're getting the grant, how has that affected your living conditions?*

Respondent: *Things have really improved now and my children's needs are covered. It's a relief for me because now my children are happy, especially the ones who are at school. I have a child in matric, and my girl here was doing Grade 10 but she had to drop out.*

Interviewer: *(To the daughter) And what made you drop out?*

Respondent (daughter): *I was short of a lot of things, which my mother couldn't manage.*

Formal salaries are the main source of income for only 10% of households, while 80% of households receive social grants from the government. These include disability grants (R820), old age pensions (R820), care dependency (R820), foster care grants (R560) and child support (R190). The household average is R905 in social grants received monthly, with 37% of households receiving grants of R1 000 or more a month.

Forty three percent of households receive disability grants relating to AIDS illness and 27% of households receive one or more old age pensions. One household receives one old age pension, two foster care grants and seven child support grants, totalling R3 270 a month.

Monthly income data was collected in estimated income bands, so we could not calculate average household income. The percentage household income within different income bands is as follows: no monthly income of less than R500 (7%); R501 - R1 000 (34%); R1 000 - R2 000 (41%).

Table 1: Possessions owned by the household or a member of the household

| | |
|----------------------|-----|
| Radio | 70% |
| Television | 53% |
| Computer | 0% |
| Refrigerator | 43% |
| Telephone (landline) | 20% |
| Mobile phone | 57% |
| Motor car | 0% |

Table 2: Self-rating of socio-economic need

| | Current survey |
|---|----------------|
| We do not have enough money for basic things like food and clothes | 37% |
| We have money for food and clothes, but are short of many other things | 60% |
| We have most of the important things, but few luxury goods | 3% |
| We have money for extra things such as going away for holidays and luxury goods | 0% |

Burden of AIDS care

Here we present key descriptive features relating to the burden of AIDS care per household.

Forty percent of households have a currently chronically sick person in the household. Chronic illness was defined as someone who is bedridden

for more than a week at a time during the last three months, who feels sick and remains in the house all or most of the time, or who rests most of the time.

Some households were caring for more than one sick person and 17% of the households have two (10%) or three (7%) chronically sick people who have been diagnosed with HIV/AIDS.

Some of the households had proportionally higher burdens on carers because of the high proportion of sick household members. Three of the households had only two members, with one being sick with AIDS. In one household the chronically sick person lives alone. In some cases, although this was not quantified, it emerged that the primary carers are themselves HIV-positive. In one case a mother and daughter both suffer from HIV-related illnesses and are primary caregivers to each other when the other is sick. In two cases the primary caregiver looks after more than one person.

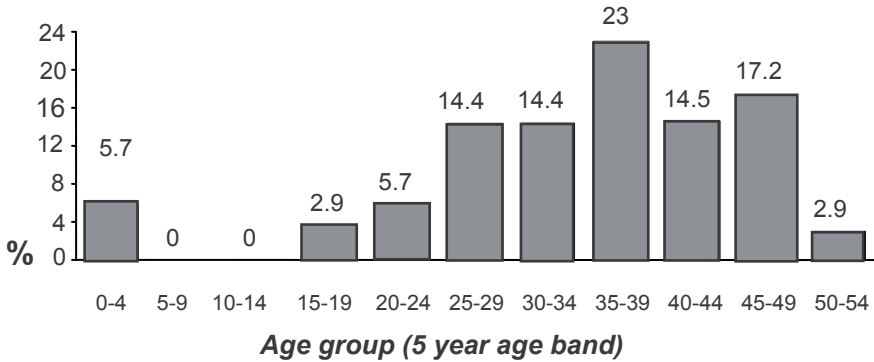
The average age of primary caregivers was 43 with a range from 17 to 88 years. In 93% of the cases the primary caregiver was a woman and usually a family member including wife, sister, daughter, grandmother and cousin. In only one case was the caregiver a friend and not part of the family.

In 63% of cases there is some external help with care (23% from government clinics; 40% from NGOs/CBOs/FBOs). Forms of assistance include: food (plate of food/bread three times a week; food parcel once in two months - although food support has diminished since the introduction of disability grants for AIDS sufferers); transport; counselling; education; occasional visits to check on health and well-being; quarterly support group meetings; treatment monitoring and support; prayer services; provision of medicines and a wheelchair (three of the respondents were wheelchair-bound as a consequence of HIV-related diseases); social support through visits; communication. These visits range from once a month (41%) to daily in the case of severely ill people.

At least 12% of participants in the study have borrowed money to cover costs associated with care, including: buying food; transport to medical and social service facilities; medicines; and electricity. Amounts borrowed for meeting these costs are modest, ranging from R20 to R150.

Only one of 30 households was caring for children (two) under the age of 18 who were from another household, but who now stay in the household because one or both parents have died. In this one case the mother was known to have died of AIDS.

In 21 of 30 cases (70%) the sick person has to share a room with others and in one case the family all live in one shared living area ("live, cook, eat and sleep in the same room"). This is especially problematic given the need for privacy in washing sick people and given that sick people are often restless at night and need to move around or have lights on. For the remaining 30% of cases, space was not noted as a problem, and in 20% of cases the sick person lives in a room alone.

Figure 3: Age bands of those sick with HIV-related illnesses

The type of care provided to household members sick with AIDS includes the following activities: buying and cooking food, physical care when bedridden, washing their clothes, collecting wood or water, spending time with the person to avoid loneliness, providing encouragement, monitoring taking of medication, preparing a special diet, carrying the person to bed or to the toilet, assistance with moving around the house, assistance with child-minding, accompanying the person to the clinic, bathing, cleaning linen, dressing sores and administering treatment and collecting treatment from the hospital.

It is important to note that the burden of caring for a sick person can be quite intensive and might, for example, involve changing of dressings each day. When this is neglected it can have terrible consequences. A homecarer describes the situation of one person who was supposed to be cared for by family members at home, who had been trained by care workers for the task: "We don't work on weekends, which means we sometimes did not go for up to two days. We got there on the Monday and the house was filthy; where she was lying, you would think that it was a dead body due to the number of flies and the stench. She was moaning in pain because her dressing had not been changed for days. We were told that she could not speak because of the pain."

This case shows the burden of caring intensively for someone who needs constant attention.

The care workers interviewed attested to the need to clean and wash patients constantly, to keep cuts clean and to manage the sick person's pain. All this is an unusual burden for family members living at home, in contexts where there are sometimes no basic services and no easy access to transport.

SERVICE ACCESS AND RESPONSES TO MARKETISATION

Financing of free basic services

Municipal funding for free basic services concessions is supplied through the equitable share fund made available to municipalities through the National Treasury. In Makana Municipality this is specifically allocated for only indigent people and amounts to R20-million annually. There are also concessions for pensioners. However, many pensioners apply for concessions as indigent people, rather than as pensioners, because pensioner benefits are smaller.

Uncertainty about payment for services

- Free electricity was only offered once and the household “never got it again”; they were not sure how much they received or are entitled to.
- A respondent’s RDP house was bought from someone else. The previous owner did not pay any rates on it. They are also not paying rates, although the Municipality has not said that rates don’t have to be paid. They hope that they won’t one day be landed with a large rates bill.
- The debt on the water account does not decrease even though this R50 is paid every month and remains at R11 879,40.

The indigent concession rate at the time of data collection was as follows: 100% for a household income of less than R700; 75% for R701-R1 000; 45% for R1001-R1400 or the equivalent of two pensions (when pensions are raised).

The Municipality is currently R100-million in debt due to arrears on services payment, which is money it owes for unpaid service debts. This is apart from the R20-million it annually receives to provide concession electricity.

The system for obtaining concessions is time-consuming and confusing. Research respondents told researchers contradictory explanations about how the system works. Many of the respondents reported unresolved or ‘in-process’ applications.

A number of respondents had made specific requests to the municipality. In four cases the municipality agreed that they would pay R50 a month for all services. Three others were allowed to pay 'reduced' amounts on rates, ranging from R60 to R200, and reported that they have difficulties paying this. One other applied to not pay at all as she is unemployed, but she had not heard or followed up on the outcome. One made a request not to pay and this was granted. One home owner reports that that she was told to pay "whatever I can afford in 'rates'". She pays R100; she explained that R50 goes to the water account and the remaining R50 is for 'rates'.

There is some confusion about the 'rates' part of the payment. Firstly, the concessions are often not reflected on the monthly accounts. Respondents in some cases responded "I don't know" when asked about the status of their applications or about what they owed and were entitled to. Some respondents tended to merge rent, rates and basic services charges in their understanding.

Secondly, there are a number of inconsistencies in the manner of applying concessions. In some cases, rates (often reported as 'rent') are not levied, until the building process in the whole area is complete. The households in such cases have not paid so far because they have not received an account for more than a year.

Eleven respondents said that their applications for concessions or extension of concessions had been unsuccessful. They were told that they were not keeping their payments current, or they had failed to pay agreed concessionary amounts by previous arrangement with the municipality. Many were refused concessions because they receive grants (including pensions, disability grants) which together disqualified them from receiving indigent concessions.

"I cannot consider her (sick person) grant as an income since it all goes to cater for her special needs. We buy the food she has to have and boosters and stuff for her. There is also an additional R190 for her child, out of which we pay R110 for his transport. I also get a disability grant which enables us to attend to household needs, although there's a lot that we cannot afford on that small amount. Like right now the child cannot have most things required for school, especially if they need to have it urgently. This forces me to go out and borrow to meet these needs."

One respondent said that she was turned away when she applied for a concession because her household received permanent but restricted access to water, and this was the equivalent of a concession. Another said she did not receive a concession because the members of the household could not afford to pay the amount agreed to in previous discussions with the municipality. One respondent had to acquire an affidavit to the effect that he could not afford the required R280.

There is also confusion surrounding water cut-offs. The municipality may turn off water when there is not payment, but does not seem to do it systematically or consistently. In one case, the municipality turned on water which had been cut off after a concession agreement had been reached to pay less. Households sometimes push for these agreements (although they may not consistently pay even their concession rates) as a way of getting reconnected.

Most importantly, ways of managing debts involve cut-offs of water do not allow for provision of the free basic allowance. The marketisation of water services has meant that those who default on payment agreements to cover arrears are refused their basic allowance. Below, we report the incidence of this in the study sample. However, we were not able to establish from municipal officials how often or how long they cut water off.

We now consider the situation regarding provision of each of the basic services and the relationship of this to AIDS care.

Water provision in Makana

Everyone has the right to have access to sufficient water. (Bill of Rights, Constitution of South Africa, Section 27 (1) (b))



Yard taps are the only source of water for many, and this is often restricted.

The following table reflects the water sources available to survey respondents in the study:

Table 3: Levels of Water Services

| | | |
|--|--|-----|
| What kind of water service does your household have? | One or more taps inside the house | 3% |
| | A yard tap only | 77% |
| | A communal tap within 200 metres of the house | 10% |
| | A communal tap more than 200 metres from the house | 10% |

Government's policy is to ensure that all South Africans have access to a basic water supply through a two-part programme. R1.2-billion is spent annually on basic infrastructure, which at the 2005 rate was providing over one million people a year with new water supplies. The National Treasury funds local government to ensure that no one is denied access to water because they cannot afford it; and it is estimated that 27-million people already benefit from free basic water.

Since 1994, water supply infrastructure has been built for 1.72-million people in the Eastern Cape alone, half the original backlog. Plans are in place to eradicate the backlog by 2008.¹⁸

The Makana Municipality claims to provide piped water on every stand in the designated area and there are no officially designated areas that rely on communal taps. Those who use communal taps live in so-called informal settlements. We note that there has been a significant improvement in water infrastructure, as the 2001 census indicated that 1 580 households in the area did not have water available on the stand.

According to municipal records in June 2005, 70% of stands had water provided to a yard tap only, while 30% of households had an in-house connection. According to the census of 2001, only 7% of households had water within dwellings, thus representing a significant improvement over the intervening four years.

The only houses in the area which have no 'stand water' are located in informal housing areas where there are no municipal services provided. In mid-2005 this was estimated to affect 580 households. The municipality hopes to move these communities to new housing development areas. In the meantime, it is reluctant to establish basic services for them, because of the infrastructure costs involved and to avoid residents wanting to remain in areas not zoned for residential development. The result is that these residents are without water. They carry water to their dwellings from formal residential areas where there is piped water. They have to obtain water from residents of formal areas, sometimes at a cost, as water is available only on stands and not on the streets.

Interviewer: *And where is the tap?*

Respondent: *It's a distance away, you have to go down that way and it's some distance off.*

Interviewer: *So, quite a distance, quite far. And what do you use to collect your water, and how do you bring it to the house?*

Respondent: *We use a bucket. And as I am sick, I am not able to carry out that task, so I take the small bucket and make several trips to the tap.*

Interviewer: *Until that big one (20 litres) is filled? (Yes.) And roughly how many times a day do you go back and forth from the tap?*

Respondent: *It depends on what I need to do with the water. Sometimes I have to do the washing and this means several trips, perhaps three or four times. (The respondent and her partner are both HIV-positive and are the only members of the household.)*

Restrictors

All households in the township areas covered by the study are said by municipal officials to receive an allowance of six kilolitres of water a month. When a household exceeds this amount, a restriction on the flow of water is introduced. The 'trickle system' of dripped water is not applied in the area, but a 'stream' system is used whereby a weak flow of water is provided. This involves fitting of a flow control mechanism and this is usually applied when a household has consistently overused its quota.

Stands with a tap in the yard as the only water point do not have to pay for water on the basis of amount used. They pay a flat rate of R10 per month, which is considered a connection fee. This charge may be dropped in the case of very poor households if they apply and pass a means test. For water piped into houses, meters are supplied and in addition to a basic connection fee, water must be paid for beyond six kilolitres. Ninety percent of such households cannot or do not pay for usage beyond six kilolitres and most are placed on restricted flow systems.

"Water is restricted and this is a huge problem as it is extremely slow. You sometimes end up coming back with your container half-full as you can't wait all that long."

Interviewer: *So this R60 is manageable, every month?*

Respondent: *Not always, for instance we haven't paid in two months because we can't afford to. So he'll have to pay double the amount now.*

Interviewer: *And if it has not been paid, what happens?*

Respondent: *The water gets cut off.*

Interviewer: *After how long?*

Respondent: *Maybe if he doesn't have the money he has to borrow it?*

Interviewer: *What I meant is, how long does it take for the water to get cut off, after it has not been paid?*

Respondent: *If you haven't paid for two consecutive months, they cut it off on the third month.*

It is notable that 71% of respondents feel that the price of their quota of water is too high, while 29% feel it is about right. In reality they do not realise how much they are paying for the water itself as the R50 a month that most are paying covers the water connection as well as refuse removal costs. Respondents were not able to account for the amount of water they use, as it is not reflected on the account. It is also notable that people are in effect paying for their right to water (connection charge), irrespective of how much it costs.

Water problems

- Of the 56% of households in arrears for water payments the amount in arrears was R7 150.
- Most respondents were unaware of their right to free water.
- 27% had experienced a complete water cut-off in the past two years on account of not paying water bills.
- Respondents reported carrying water from communal taps and schools from various distances up to 800 metres.

Only 44% of respondents were not in arrears of payments. Of the other 56% there was an average amount in arrears for water payments of R7,150. This means that they will probably always owe money and

will be placed permanently on a restricted flow system.

Most respondents seemed unaware of the promise of “free water”. When asked whether they receive any “free water” as promised by the government, 67% said no and the remaining 33% were unsure. Furthermore, 27% said that they had experienced a complete water cut-off in the past two years on account of not paying water bills. This is a significant problem, considering that these are all families caring for sick people. For 23% of the sample, water cut-offs had created problems in terms of their ability to provide care for those in their household with AIDS. For 20% of people experiencing cut-offs these lasted for more than a month. In one case the water was cut off for more than six months.

When the water is cut off and for people living in informal settlements, carrying water from communal taps is a significant burden. Respondents reported carrying water from communal taps and schools from various distances up to 800 metres. This means people have to ration their own water use very carefully.

Some collect water from nearby cattle dams and boil it before use. Others have to pay for assistance. One said: “I was unable to fetch water myself and had to depend on children whom I had to pay to collect the water.”

As is the case with electricity, some of the householders are confused about what to expect in dealing with the officials about water supply and regulation.

Interviewer: *And on the question of water you touched on earlier?*

Daughter: *They said debts would be scrapped and a new process would start, this was said on the day we went to submit applications for this electricity. But nothing has changed because we still get the account reflecting the same amount we owed before, about R7000.*

Mother: *When they called us they asked us to bring these water accounts and the card you buy your electricity with. There were two points there, one for water and the other for electricity. I went through both processes, but nothing has come of any of it. But fortunately, the water has not been cut off. The water guy was here yesterday. He does not come in but just goes to the meter over there so we don't know why he was here.*

Even when water is freely available at a communal or yard tap transport, storage and household management of water are problematic. Carrying it is tricky, too, as larger containers are too heavy, and smaller containers require more frequent trips.

To overcome this problem, some residents buy water from neighbours. One respondent reported paying R5 for 20 litres of water. There is also a

tradition of borrowing water from neighbours, but this is limited to small amounts, as ultimately they face the same predicament.

Water and AIDS care

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"Most of the people we see have diarrhoea, rash, bedsores." (Homecare worker)

The government has capped the free water allowance, but six kilolitres is clearly not sufficient to cover the needs of HIV sick individuals. Secondly, it does not take into account the number of people in a household since the state has worked with an average household of 8 persons based on supply to an erf or stand. Yet in Grahamstown many households occupy a stand. The number of people per stand is often higher than eight. The system of capped free water allowance and prepaid water meters is currently a matter before the High Court.¹⁹ It is argued that this discriminates against the poor who have to do without water if they use more than 25 litres per person a day (based on six kilolitres per household per month and assuming a household of eight persons). Where flush toilets are used this amounts to two flushes of a toilet. The United Nations considers the average person needs 50 litres of water a day to meet their water and sanitation needs.²⁰ The need for water is considerably greater where people are caring for people sick with HIV-related diseases. In effect, a permanent rationing of water for the poor is set in place.

AIDS care increases water consumption

- *"I use water a lot, especially when I'm sick with diarrhoea. Sometimes I mess the couch over here if I'm very sick, then there is a lot of washing to be done, and I also have to use some to wash myself."*
- *"The consumption only goes up when the sick person is bedridden."*
- *"It is difficult because the infected person is disabled and she must have her clothes washed regularly. It is worse when she has diarrhoea because she messes herself up, with more washing to be done."*
- *"More water is used as the person and their clothing have to be washed frequently. He also needs to drink more water when he is not feeling well."*
- *"More water is used when someone is sick with diarrhoea."*
- *"More water is needed to wash clothes and to cook special foods."*
- *"It's very important that we receive water. It would be impossible to look after the sick person as this requires use of larger amounts of water."*

- *“The more sick she is, the more water she uses for washing twice daily, for drinking as well as for taking medication and doing the washing.”*
- *“It makes a difference when you have a sick person as we use more water for washing both the patient and his clothes/linen more often than is ordinarily the case.”*

Water and self-care

Ready access to water and assists people with HIV-related diseases to care for themselves and its lack creates dependence and leads to self-neglect.

- *“I can cook for myself and bathe when there is water. It gets difficult to cope when we have none as I can’t wash or take treatment.”*
- *“Water allows me to grow a vegetable garden. If it is not there I cannot do this.”*
- *“We don’t do the washing for instance, even if you would have liked to. It’s beyond my control because I don’t have the strength to do it (collect water).”*
- *“It is very difficult to cope without water to drink, take medication and flush the toilet.”*
- *“Shortage of water sometimes makes me feel bad because the people taking care of me struggle and I can’t get food on time to take my medication.”*
- *“If we have water I can wash my own clothing, cook and clean the house when I’m feeling better.”*
- *“Access to water has enabled me to take proper care of myself; it’s the most important aspect of being sick.”*
- *“We sometimes have to be sparing and maybe skip bathing when there’s not enough in the house.”*
- *“I am scared to go and fetch water at night and if there is none in the house, I simply do without.”*
- *“Access to water enables me to take medication properly and to clean myself. I’m unable to fetch water and am constantly short, as the tap is very far away.”*

Only 10% of the households claimed they do not experience any difficulties with their limited access to water. They have adapted to it and have ‘enough hands’ to collect water. But most (90%) have found

the limited water through flow control extremely restrictive, especially smaller families with high burdens of illness.

The following statements by respondents indicate the consequences of water cut-offs:

- *“There was not enough for cooking and washing.”*
- *“The sick person’s clothes could not be washed as there was not enough water.”*
- *“We couldn’t wash as usual, [and] had to restrict this to once or twice a week.”*
- *“We had to save water. We did not throw away water used for bathing but kept it to flush the toilet. This was really difficult when the patient had diarrhoea.” (Problems related to toilet flushing were raised by most respondents who have toilets.)*

Challenges of water supply

- *“We sometimes run short at night or sometimes have to pay children to collect the water for us.”*
- *“We have to carry a 20 litre bucket from 800m away, which is difficult when it is cold or raining. We then have to restrict its use and cannot use it as desired.”*
- *“In the absence of the caregiver it’s difficult to get water to the house as about 25 litres is used normally, and still more when the wash has to be done. [It’s] especially difficult when you run out at night.”*
- *“The tap is quite a distance away and in adverse weather it becomes difficult to have access: we have to save to make sure it lasts through the night and for the next day.”*
- *“It’s difficult as we have to collect water from a communal tap. It is especially hard on my child as I cannot do it myself, especially at night.”*
- *“It gets very difficult for her when I’m not there to collect water, which has to be done about four times a day from the communal tap 200m away. She has to do without and can’t use it as desired to do the wash, clean up and for taking medication.”*

Electricity access and free basic electricity provision

Makana Municipality is the local government authority responsible for

services planning and delivery in Grahamstown. However, in the areas in question, electricity is supplied by the national electricity supplier Eskom, and the municipality simply manages payment. All houses occupying municipal stands are supplied with meters, and in recently built 'RDP' houses, largely occupied by poor residents, supply is limited to two plug points and one light point per room. Fifty units (50 kWh) are issued free per month to pre-paid meter users and this applies to all households in the designated area. But the system of issuing pre-paid electricity requires users to buy electricity, as the free electricity is issued in the process of purchasing. At least this is the understanding of most respondents. In fact, at two of the four points, which are a few kilometres distant for some respondents, it is possible to obtain the free electricity without payment. But few people seem to understand that this is the case.



Electricity infrastructure has been installed but the reality is that for many, access to electricity is limited or non-existent.

"We were told by the Ward Councillor that there's this concession for people getting an income of less than R1 000...people can go to the local community hall to apply. I went to the hall to apply, and there are people there ready to receive our application...you can do your affidavit there...here's a list of people sitting at different tables. We were told that every time you go and buy electricity you would also get a 'free card'; you get additional free units every time you buy.... When it has been granted they add it to your units when you go and buy, and you only know then that it has been granted. You're given a voucher for the units you have bought and the additional ones are reflected on the voucher."

The households spent on average R82 a month on prepaid electricity (ranging from R10 to R300). This amount means they even with free basic electricity they still spend about 10% of their household income on electricity.

Attitudes to having prepaid meters are generally positive. Of all the respondents, 83% said 'yes' to whether they like prepaid meters, 9% said 'no' and 4% were 'unsure'. This is despite difficulties in buying prepaid electricity: vending machines are few and far between, they are not available over week-ends and buying electricity may involve transport costs.

Reasons for liking prepaid electricity included:

- *"Because on account you would end up using more than you can afford and on prepaid you can manage how much you use." (Many people said this.)*
- *"It's better because there will always be electricity, even if it's for a small amount. Also, when you run out you can always borrow a small amount from the neighbours."*
- *"How and when electricity is used is within [our] control."*
- *"We cannot afford the alternative (account) and prepaid is cheaper."*
- *"Because you can buy electricity for R10 and you can budget for how much you spend, instead of getting a high bill that you cannot afford to pay, leading to arrears that you can never pay, and cut-offs." (Many people said this.)*
- *"Prepaid is better because you can keep up with your own use of it and can borrow money if you need more."*
- *"You can always buy electricity, even if it's a little, instead of having none at all."*

These reasons all attest to respondents' preference for a system which they can control rather than being subject to the system of arrears and cut-offs which they have experienced with water. Interestingly, few respondents said that the system of electricity provision was unfair or contrary to any entitlement that they might have to free basic electricity. Perhaps because they had no alternative, people seemed to accept the system of buying electricity and getting a little 'free'.

Electricity and AIDS care

Electricity use increases when caring for people sick with HIV-related illnesses, but it is perceived as expensive and frequently there is no money to buy it.

Respondents attested to a strong link between AIDS care and electricity:

- *“With electricity you can take proper care of the sick person and carry out activities like cooking, cleaning, washing and heating, which are a necessity for the sick person.”*
- *“It’s essential as it makes a difficult life bearable. Without it you can’t take proper care of yourself, like you sometimes skip bathing and you can’t always eat as you wish.”*
- *“They sometimes have to use the toilet in the middle of the night and need to have lights. It presents safety problems as it is dark at night [outside toilets].”*
- *“Sometimes you need hot water quickly and it takes ages to heat it on the paraffin stove.”*
- *“Sometimes a person gets very ill at night; it’s difficult to do anything with no lights.”*
- *“The water has to be boiled before it is given to the infected person.”*
- *“Use of electricity has to be restricted, which is difficult as more electricity is used for cooking and bathing especially when she is sick with diarrhoea.”*

Interviewer: *And do you have electricity in the house here?*

Respondent: *No, there’s no electricity.*

Interviewer: *You don’t have it yet?*

Respondent: *No.*

Interviewer: *And this entire area has no electricity?*

Respondent: *No, none whatsoever, not in this neighbourhood/area.*

The main secondary source of energy for cooking and heating is paraffin: “We use a paraffin stove because we cannot afford electrical appliances, nor would we be able to sustain use of electricity if we had such appliances.” The use of paraffin is said to create fumes. These can cause problems to the sick person, including headaches, nausea, sore eyes, chest pains and coughing. Such symptoms were mentioned by seven respondents, which they attributed to the use of paraffin. Alternatives for cooking are

use of wood which can only be burned outside because of smoke, but this is not possible in bad weather. Heating quantities of water for bathing a sick person is a problem and often has to be done outside on a wood fire.

All the households in informal areas have no electricity. In such circumstances it is clear that it becomes much harder to care for those sick with HIV-related diseases.

Sanitation



The bucket sewerage system remains a part of the lives of many in Grahamstown's townships

In August 2005 there were four sanitation systems used in the greater study area: the bucket system (22%), water-borne sewerage (50%), external pit latrines (21%), no basic sanitation (7%). There are plans for the bucket system to be replaced by water-borne sewerage. Infrastructure is being developed for this, but is not yet connected for one-third of bucket-system households. Sanitation costs are included in a basic services fee for sanitation and refuse removal, which does not apply in the case of indigent households.

Interviewer: *You don't have water...I know you said you can fetch it from the communal tap, there's no electricity... and I'm assuming the toilet is outside, right?*

Respondent: *It is outside, I built that toilet myself. I paid some kids to cover it with canvas because it is such a distance to the bush! ...We've been using the bush for years...For nine years there has been no toilet. Now we were given buckets by our mayors.*

Diarrhoea is one of the more common manifestations of advanced AIDS and the management of sanitation is a major part of AIDS care. In the words of one respondent, "It is important to have a flush toilet as it can be

thoroughly and regularly cleaned.” Easy and hurried access to toilets was also perceived as a care priority.

But most households surveyed did not have water-borne sewerage. In some cases there was water-borne sewerage inside the house, but no taps except in the yard, making washing of hands after using the toilet difficult.

Most respondents hate bucket toilets and external pit latrines, and the quotations below show why:

- *“When the patient has diarrhoea they may need to go for about six times a night, a feat that is difficult especially when it is cold and raining.”*
- *“I need to always accompany her at night for safety reasons, which is very difficult at night especially when she has diarrhoea. This may be up to three times a night.”*
- *“It is difficult to get there when the person is sick, they often soil themselves before they get there. At night and on rainy days this just gets impossible. The toilet also overflows when it rains and it may take weeks for this to subside.”*
- *“The sick person gets exposed to cold and may get flu when they have to go outside at night. This is even more burdensome when they have diarrhoea and have to be accompanied several times a night.”*
- *“The toilet is far and I am unable to access it at night when I am very ill. I end up messing my bed then the linen has to be cleaned.”*
- *“It’s difficult to use the outside toilet at night especially when I’m sick or when it’s cold and rainy; I develop flu and it takes a long time to get better.”*
- *“The sick person is scared to go to the pit toilet; she feels it is unstable and that she may fall in. This is especially a problem at night with no light.”*
- *“It is very difficult as the person I care for is paralysed from the waist down; I have to clean up every time she messes as she cannot go to the toilet outside.”*
- *“The bucket system is not healthy. Collectors often have spills, which are a health hazard.”*
- *“The buckets are collected (only) twice a week...the odour becomes unbearable when it is hot.”*

- *“When it has rained the pit latrines overflow ...and everything floats to the top. This is so unhygienic and exposes the sick person to germs.”*
- *“Dogs push it and everything inside gets exposed. Sometimes it is not collected in time and there are flies everywhere.”*

There is also a problem of disposal of waste water in general. If there is no water in the house, there is no drainage system. The water either needs to be carried to a pit latrine for disposal or disposed of in the yard or on the street. Toilet buckets cannot be used for this to avoid filling them up. Needless to say disposing of such waste water in the yard or on the street poses a health hazard, not least for children who have no other place to play. The poor sanitation services are detested.

It is evident from the above that AIDS care poses special sanitation problems and that the current arrangements are seriously deficient, and pose probably the greatest need in relation to AIDS care.

Refuse collection

Refuse collection is paid for as part of a R50 service levy, which includes a water connection fee and quota. Indigent households are required to pay a basic services fee of R10 for water connection, which also covers refusal removal.

Respondents were asked if there was anything important about how refuse is collected in relation to caring for a person with HIV/AIDS. Most responded that refuse is collected regularly. They also showed awareness of the need to maintain a generally hygienic environment and to avoid germs and flies.

Some people mentioned minor problems with the removal of rubbish. However, in general there was a strong sense that this service was reliable, valued and largely unproblematic, especially for discarding waste products.

Social Support

AIDS-affected households responded in mixed ways to questions about neighbourly support.

Table 4 : Perceptions of responses of neighbours

| Type of response ²¹ | n | % |
|--|----|----|
| Negative responses from neighbours | 7 | 23 |
| Positive or supportive responses from neighbours | 11 | 37 |
| Negative responses from own families | 2 | 7 |
| Neighbours do not know | 4 | 13 |

The following statements report negative reactions:

- *“The response is very negative; they swear at me and also pass indirect remarks and negative labels.”*
- *“Some of the neighbours make negative assumptions about her (the sick person), but have never asked her openly about her illness.”*
- *“Some neighbours pass stigmatising and labelling remarks to my children; they swear and refer disrespectfully to my health.”*

Interviewer: *And your family, how did it go with them, the family and your children? I assume they know?*

Respondent: *My family...there’s some strife between me and my family, because when they knew that I was sick...my mother and my sister...it was a situation where I couldn’t touch anything, or even wash the dishes...after I had told them. I realised that it would be better to keep my distance. And even with my own children, there are those I haven’t told, like the eldest because he does not care about anything that happens around here.*

Some statements indicated respondents anticipated rather than experienced negative responses. For example:

- *“The neighbours do not know. The family cannot be open as the community is very discriminatory towards infected people. They do not know that there is a person with AIDS in the household.”*
- *“She is not willing to tell them about her HIV status because she’s afraid they will gossip.”*

Homecarers described various expressions of stigma they had come across. For example:

- *“I have a client whose husband made it known to the neighbourhood that she is HIV-positive during a fight they had. She could not step outside her home afterwards, it was really sad.”*
- *“We had a case where children had fought and the neighbour told the child off, saying her mother had AIDS.”*

But there were more positive perceptions of neighbours’ responses than negative ones. Examples include:

- “They have accepted her (the sick person) and are quite helpful.”
- “They are sympathetic; they visit often to encourage the infected person.”
- “The one household that knows is responding positively.”
- “Nothing negative has been said or done.”
- “The response is positive – they sometimes have a hard time believing that I am HIV-positive because I’m still in good health as I take good care of myself.”
- “Neighbours have responded positively and are supportive.”
- “Only one neighbour knows and has shown care and love. The rest do not know, but still visit as they know that she is sick.”

A homecarer reported the following anecdote regarding care responses in the neighbourhood: “We once got a report about a woman who was sick and was being neglected by her husband. Her neighbours came to us to report that the husband locked her up and mistreated her. We had to call in the police because on numerous occasions no one came to the door when we knocked. When we ultimately got in, we found her lying on the bed – it was wet through, and there were maggots all over her and on the bed. There was excrement all over the bed she was lying on. She was disabled and had had her legs amputated before she got ill. We took her to the hospital and she’s still there. I don’t know what happened with the husband. So my point is that had it not been for the neighbours then we would not have known about her case.”

Why do some families experience strong stigma, while others experience strong support from neighbours? It is likely that pre-existing relationships between and within families would make a difference. It also seems that anticipated negative responses and secrecy may partly create the negative responses they anticipate. Families who are more open and supportive about AIDS in the home tend to be perceived and responded to by their neighbours with less negativity. They are also more receptive to outside help and hence receive it. We conclude that while there is certainly stigma and fear of stigma, there seems to be a prevailing attitude of community support rather than stigma. If households are open about the problem, and neighbours recognise their need, they will tend to help.

Interviewer: Do your neighbours chip in to help when they can see that the going is rough?

Respondent: Yes, they come. The one who is sick is somehow related to my husband, so she often comes to offer help. She will come over to check if we still have basic things like tea, and this is helpful because sometimes there's nothing, and even my sister-in-law may have run out of stuff. It's almost as if she can sense it when I have nothing. Her help is always just at the right time. There's also someone from church to whom I often go for help.

23 out of 30 respondents (77%) noted that neighbours did provide some assistance, such as: visiting to keep the sick person company and to provide support and encouragement; help with home chores and errands; direct care of a sick person when a primary caregiver is not available; financial support for transport; provision of supplies like paraffin and food; cooking meals; provision of vegetables from the garden; invitations to meals; collecting water; calling ambulances in medical emergencies. Five respondents also noted visits from church members who come to pray with the sick person and counselling from community-based organisations.

Although households caring for people with HIV-related illnesses have higher needs for water and electricity and have greater demands and risks associated with sanitation, neighbours have no better basic facilities or access to services. They can provide support, but they cannot help with the service deficits, apart from occasional assistance such as water carrying or provision of fuel for heating and cooking.

DISCUSSION AND CONCLUSIONS

AIDS response strategy

The basic services problem faced by respondents in this study is also a public health issue, but one that has received little attention. The government needs to recognise that some basic services are vital in the face of AIDS. The government has gone to great effort to support home-care, including training and supporting community volunteers working at clinics and supplying them with basic provisions for their work, but there has been little recognition that adequate home-care is simply not possible under existing conditions. The same might be said of efforts to promote food.

There can be no effective food-gardening as a response to AIDS nutrition needs, when water needs to be carried 800 metres for household consumption, and home-care as an AIDS-care model is seriously compromised by lack of water, poor sanitation and no access to electricity.

There is no significant AIDS strategy or advocacy project in South Africa that addresses the connection between basic services delivery and AIDS care. There has been limited recognition of the meaning of the inadequate basic services for AIDS care in addresses by key public figures, but no organisation has strongly worked to link the problems of service delivery to AIDS care issues.

It is a systemic problem in this country. It involves the failure of public health policy to truly engage with what has been known for many years, that health care cannot be divorced from needs for adequate housing and basic services.

There is a strong need to raise the concerns highlighted in this study to the forefront of AIDS care, support and treatment advocacy.

Municipal responses to AIDS

The municipality has not recognised the special crisis facing AIDS-affected households and there have been no attempts to address this systematically. The municipality does have a primary health care department that runs a number of clinics providing services to HIV-positive people, including homecare services. However, there is no link between this municipal function and the basic service delivery functions.

Furthermore, there is no municipal strategy for dealing with AIDS, although the municipality does have a special projects unit which lists AIDS as a programme area. The municipality also convenes an 'AIDS council'

but its development, a co-operative effort of AIDS agencies in the town, has been hesitant. Many municipalities in the province have formed such councils, but the initiatives have not captured municipal attention as important programmes worth investing resources in²² and such initiatives are generally far removed from the core business of municipalities.

It is often claimed that the drive to establish HIV/AIDS councils in South African municipalities is yet another example^{23 24} of an unfunded municipal mandate because there is no finance set aside to support this. But there is a further problem: efforts to develop municipal HIV leadership²⁵ have been largely unsuccessful due to lack of any guiding policy, strategy or framework. No agency has adopted a leading role in this regard²⁶ and the autonomy of municipalities has meant that the issue is not prioritised on any national or provincial agenda.

In general, there has been a very poor response to HIV on the part of South African municipalities (apart from a few larger towns and cities).²⁷ Although the South African Cities Network has made a concerted attempt to keep AIDS on the municipal agenda, its efforts are limited to South Africa's largest cities. By contrast, smaller municipalities have not achieved much and there is relatively little support from provinces or other agencies to support local government responses to AIDS.

Cost recovery and free basic services

The municipality strives to meet its goals of providing service delivery while hoping to tackle debt. But it seems highly unlikely that such arrears will ever be settled, given the high levels of arrears and the monthly incomes of households that mostly depend on grants.

There seems little chance that HIV-affected families will ever be able to meet their basic health needs without some form of further assistance in the current environment. Right now, water may be cut off or restricted after non-payment, sanitation is unsatisfactory and free basic electricity is supplied only when there is a successful application for being classified as indigent (and then with some difficulty because of inaccessibility to points where free electricity is distributed).

Both the local municipality and populace are in arrears to a level that is beyond relief and the situation compounds by the day. The failure of the strategy of recovering costs whilst providing basic services to those that cannot afford them must be reckoned with. It is apparent that the municipality cannot manage the sheer numbers of 'clients' requiring credit management, generated by its own cost recovery strategy. There is much evidence of inconsistency, poor follow-up and inadequate services. The strategy of marketisation is proving unmanageable and seems ill-conceived as a strategy in communities as poor as the one studied.

The municipality's attempts to create a culture of payment for services are unlikely to succeed, because of the high level of poverty in the area, made worse by the downwardly spiralling circumstances of the thousands²⁸ of AIDS-afflicted households in the area. It is quite apparent that these families use considerable resources, including basic services, while caring for the sick. This reduces their ability to pay for basic services.

It appears that the municipality is largely at a loss with respect to how to deliver a free basic allowance on its own terms; i.e. to those that it deems as qualified to receive it. The provision of free basic electricity allowance to some poor users is not known to many residents and it is accessible except at two of the electricity vending points. Otherwise, even the very poor have to buy pre-paid electricity to access free electricity. This also assumes an efficient system for being granted concessions, which has been shown not to exist. There is also no way of accommodating the greater increased water and electricity consumption needs of larger households.

The problem of servicing these poor communities should fall to the government system as a whole rather than to the local government system. The extent of National Treasury support nowhere near addresses the needs of the municipality in regard to its service delivery needs and debt. Municipalities do not receive enough funding to deal with both the payment crisis and service delivery shortfalls.

Hopefully, the findings of this research can add to the growing call to totally review and overhaul the system for financing and providing basic services in the country.²⁹

Rights

The poor are unable to pay for basic services – and they are not receiving them. There is an infringement of constitutionally guaranteed rights to basic services, when basic services are cut off.

The constitutional right to basic lights and water means: firstly, there ought to be allowance made in determination of the quantity of services to be supplied for the number of people in a household. The simple formula of six kilolitres per month per household may be satisfactory in the smallest households, but at 25 litres per person per day for a household of eight this does not match the needs of even a child. In the household in this study with 13 people, the free water provision is only 13 litres. This is the equivalent of a single toilet flush. It is accepted in the international humanitarian assistance community that 50 litres per day should be regarded as the daily consumption need per person.

Secondly, there ought to be allowance for elevated basic needs, given the different circumstances, notably for people caring for the sick at home. This study shows that basic services have multiple implications for treatment and care, and there is a need for greater advocacy on this issue. Home-based care requires considerably more water than the 25 litres per capita per day, and that is considered 'basic access'³⁰ in a medium-sized family.

Thirdly, basic services (inadequate as they are) are frequently denied to people in need. This is often a product of inconsistent, contradictory and poorly formulated indigent and other social benefits policies.

People we interviewed appear to have little sense of their rights regarding

water and electricity. This contrasts with the apparently high levels of community mobilisation and resistance around these issues in some communities in other provinces.³¹ Some respondents in this study think of access to basic services as a favour or 'gift' from government rather than a constitutional right. People pay so as not to be subject to a punitive bureaucracy that sees it as within its rights to cut off and limit water as a way of dealing with the problem of arrears and tampering with meters.

Interviewer: *How do you understand this promise of free electricity: does that mean you won't have to buy electricity?*

Respondent: *Yes, that's what they were saying. They said you will go and buy it yourself when you see that it is not enough. We are told that everybody in this area has been given this 'free' electricity, which is already in that box. The people in Vukani (a recently built area with RDP housing) have also received it. It is a gift to us from the government.*

The impact of social welfare grants

The households in this study relied heavily on government grants as a main source of household income. There has been much effort expended to extend social assistance grants over the past few years and it is evident that those eligible for such grants are aware of the availability of grants and are increasingly accessing these.

There is, however, a stark irony within the system of social assistance. Grants are regarded as income that means recipients cannot receive concessions³² and diminishes their power to negotiate terms of debt repayment for basic services. This contradicts the underlying reason for government grants, which are designed to assist people to cope with their special circumstances and needs.

Informal settlements

Informal settlements in the area studied have no municipal services, apart from access to community taps in nearby areas. The AIDS care situation in such areas is dire and the type of conditions described in this study must be recognised as a strong health-risk for HIV positive people. Some municipalities are moving to provide services to such settlements, but a systematic approach and strategy is necessary for both humanitarian reasons and reasons of containing the HIV epidemic.

Research

Support for this issue will require more number-based evidence on a national scale.

National scale research would need to cover the range of types of human settlement and service provision in South Africa. It would be important to consider those living in more rural areas, where providing basic services can be a greater challenge, but where often people are more adjusted to their circumstances, as compared to those newly settled in urban settlements where there are fewer natural resources to draw on, such as fuel for fires and water from dams and streams. It would also be important to study the context of larger towns and cities and informal settlements at their edges and centres.

Areas important to include in a national scale study are:

- the level of arrears for basic services;
- monthly costs of basic services for families caring for people sick with HIV-related illnesses versus non-affected families;
- acceptability of and impact on AIDS care of different marketisation strategies;
- use of social grants for paying for basic services; and
- quantitative comparisons of health status indicators and health histories for people with HIV under different conditions of access to basic services.

The questionnaire developed in this study has yielded interesting information and with further refinement and adaptation could usefully be adapted for a larger study.

It would also be of value in building an advocacy agenda to review the perspectives of major AIDS service and advocacy organisations that have not to this point voiced much concern about the impact of poor basic services delivery, and marketisation in particular, on AIDS care.

Endnotes

¹ Barnett & Whiteside 2005.

² Services include anti-retroviral therapy (ART), treatment of opportunistic infections, provision of home-based care, palliative care and provision of psychosocial support.

³ McDonald and Pape (2002) have outlined the crisis of service delivery attendant on cost recovery strategies for basic services provision.

⁴ Roussouw & Setswe 2004; Kiongo 2005; Lewin et al., 2000.

⁵ Kgalushi et al., (n.d.); Kiongo 2005.

⁶ Kamminga & Schuringa 2005.

⁷ Van Donk 2006, p.168.

⁸ Shisana et al., 2005.

⁹ UNAIDS 2002, p36.

¹⁰ Shisana et al., 2005, p36.

¹¹ "Black" refers to all people who were not allowed to vote before 1994.

¹² Census 2001.

¹³ Shisana et al., 2005.

¹⁴ In early 2007 there were 633 on the Department of Education's database and a total of 841 registered in combined records of different agencies concerned with orphan care. The latter, however, includes some double counting.

¹⁵ Birdsall & Kelly 2004.

¹⁶ This has not been quantified at this point, but is supported by ample anecdotal evidence.

¹⁷ HSRC 2002.

¹⁸ Mike Muller, Director General, Water and Forestry Affairs, 9 January 2006, *Cape Times*.

¹⁹ Soweto starts its water war, *Mail and Guardian* 21-27 July, p.8.

²⁰ The United Nations recognised this standard in *General Comment 15*, November 2002.

²¹ The above figures do not add to 100% as they are not all mutually exclusive categories and some families responded in a non-committal way or with uncertainty.

²² Kelly 2005

²³ Estimates from Cape Town and eThekweni (Durban) Municipalities in 2004 were that as much as three-quarters of the health expenditure by the municipalities falls into the category of an unfunded mandate and is not subsidised by provinces as it should be.

²⁴ Atkinson 2003.

²⁵ Kelly 2002; Ambert; Kelly, 2005.

²⁶ The South African Local Government Association (SALGA), the Department of Provincial and Local Government (DPLG) and national and provincial departments of health have made some attempts to deal with the problem.

²⁷ Kelly & Marrengane 2004.

²⁸ Considering the estimated 8 000 HIV positive people in the municipal area.

²⁹ Mcdonald & Pape 2002.

³⁰ Howard & Bartram 2003.

³¹ Soweto and Orange Farm in Gauteng province, for example.

³² Whereas pensioners may be granted concessions, when the total household income is pooled this concession is usually lost as the total amount may exceed the qualifying amounts.

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This project is funded by the
Canadian government through the
International Development Research Centre (IDRC)