

HIV-AIDS and the Struggle for Life

A Report by the Research Subcommittee of the Anti-Privatisation Forum

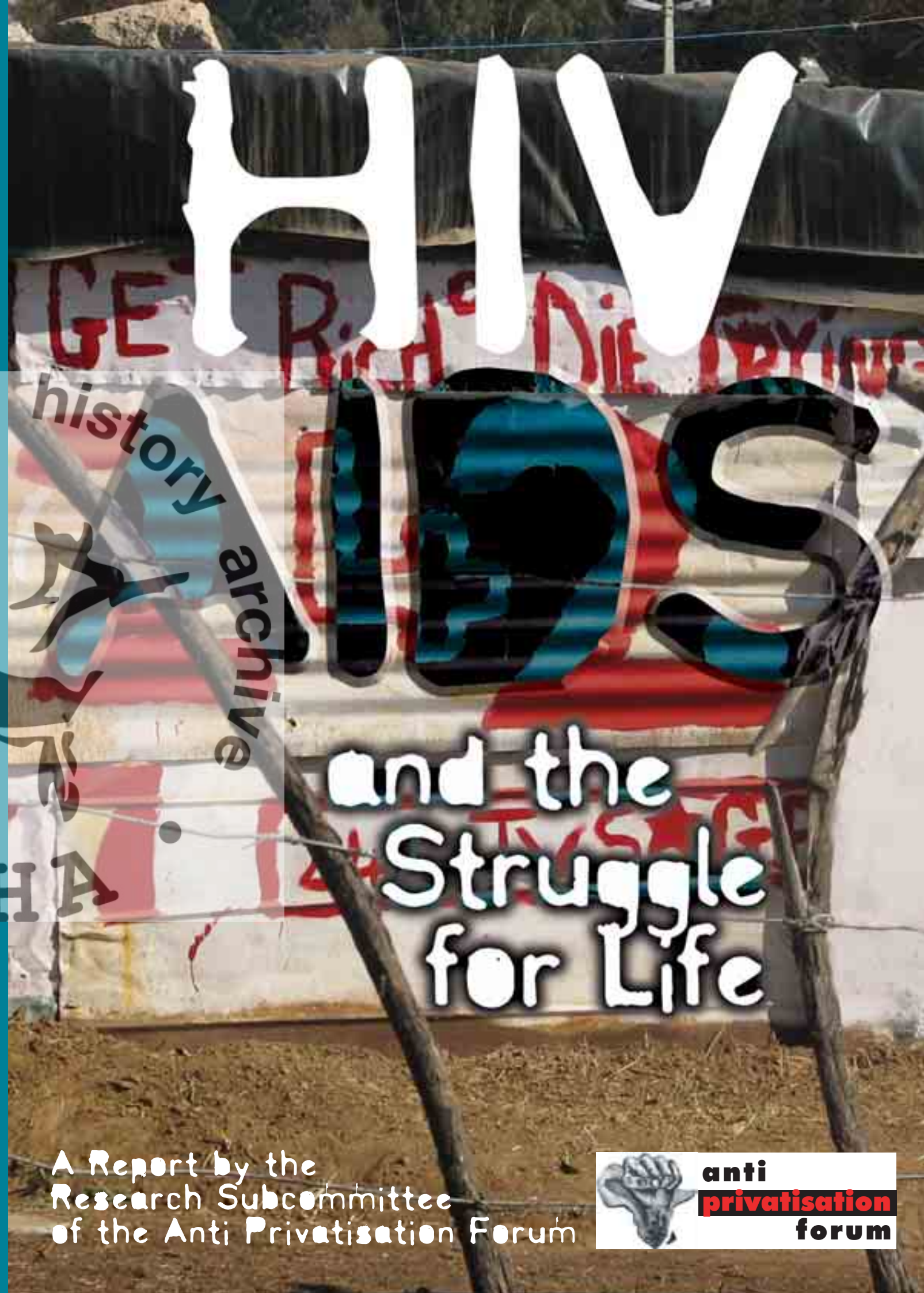
The Anti-Privatisation Forum (APF), an organisation made up of 22 affiliates in the Johannesburg region, has felt the impact of the epidemic within our communities and more broadly in the organisation. HIV-AIDS started to become a central concern for the APF when more and more activists began to fall ill or die, and arranging their funerals became an increasing and consistent activity of the organisation. Affiliate organisations then began to establish their own practices to address the impact of the disease. The fact that the problems related to HIV-AIDS were becoming inescapable at an affiliate level led to members calling for the establishment of an HIV-AIDS subcommittee in the APF. Instead of a separate subcommittee being formed, the Research Subcommittee was asked to begin a process towards defining a campaign in the APF around HIV-AIDS.

This research project is the first step the APF is making to break the silence surrounding HIV-AIDS that has permeated our struggles thus far. The research focussed on two communities, Sol Plaatjie in Durban Roodepoort Deep and Phiri, Soweto. Surveys and focus group discussions were conducted to investigate living conditions in each community, what healthcare facilities are available, and how the communities are dealing with the impact of HIV-AIDS. This report presents the findings of the research.

Anti Privatisation Forum
11th Floor, Auckland House
185 Smit Str., Braamfontein
Tel: 011 339-4121
Fax: 011 339-4123
Web: www.apf.org.za



Phiri, Soweto



A Report by the
Research Subcommittee
of the Anti Privatisation Forum



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ANTI-PRIVATISATION FORUM

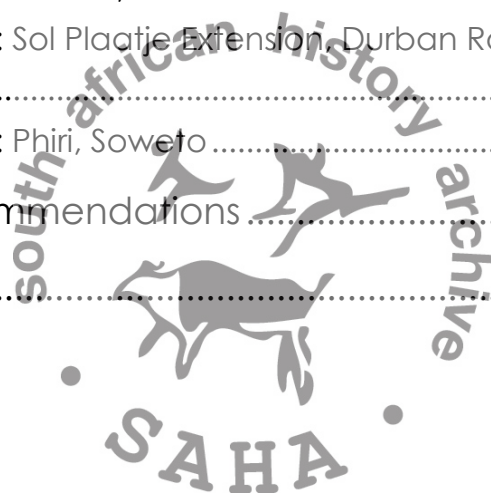


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INTRODUCTION



According to a South African Department of Health Study conducted in 2004, based on a sample of 16,000 women attending antenatal clinics across all nine provinces, 29.5% of pregnant South African women are infected with HIV (Department of Health 2005). In 2004 alone, AIDS claimed the lives of 300,000 people (Treatment Action Campaign 2005).

The Anti-Privatisation Forum (APF), an organisation made up of 22 affiliates in the Johannesburg region, has felt the impact of the epidemic within our communities and more broadly in the organisation. HIV-AIDS started to become a central concern for the APF when more and more activists began to fall ill or die, and arranging their funerals became an increasing and consistent activity of the organisation. Affiliate organisations then began to establish their own practices to address the impact of the disease. However, at the organisational level, the issue has been marginalised for a number of years. The fact that the problems related to HIV-AIDS were becoming inescapable at an affiliate level led to members calling for the establishment of an HIV-AIDS subcommittee in the APF. Instead of a separate subcommittee being formed, the Research Subcommittee was asked to begin a process towards defining a campaign in the APF around HIV-AIDS.

The APF, therefore, has not been immune to the pervasive stigma, fear and myths associated with HIV-AIDS, which so often cloak the disease and the experiences of those suffering from it in suffocating silence. In fact, the problems the APF has had in coming to terms with the epidemic and its impact on our communities and members reflect more widespread problems within HIV-AIDS activism.

First of all, HIV-AIDS infection is usually represented as a result of *individual behaviour*; however, this cannot account for such enormous variation between the countries' infection rates (or why rates of infections are always higher amongst oppressed populations within each country). This individualisation of the disease is dangerous because it obscures the socio-politico-economic factors of the epidemic. There are structural reasons why certain populations are more vulnerable to infection (women, people of colour, the poor) which have more to do with the relationship between health and deplorable living conditions, patterns of inequality, and exploitative inter-personal relations than with individual behaviour (Decoteau 2005).

"Blaming the victim is part of the neo-liberal approach to health. It nicely avoids any discussion of structural violence, which would be deeply threatening to the status quo of current international economic arrangements" (Katz 2005: 55). The HIV-AIDS crisis is not commonly analysed in socio-economic terms, and so the impact neo-liberal economic restructuring has had on this epidemic is often overlooked. This is a particularly important shortcoming of approaches to AIDS in countries of the global South.

The way in which HIV-AIDS policy is imbued with neo-liberal agendas is often complicated and obscured – on both an international and national level. Neo-liberal policy and colonisation are largely to blame for the endemic poverty that plagues the 'Third World,' which has resulted in high rates of HIV infection, as well as an inability to care for those infected. For example, World Bank and IMF policies force states to cut funding on social services (for health care, education, the provision of basic services, etc.) and impose policy restructuring at a national level, which encourages the corporatisation of state governance and privatisation of basic services. As a result, health (along with water, air, electricity, etc.) is commodified, and only those who

can afford to pay have the luxury of healthiness. "The current economic policies would rather view health as a private good that is accessed by the medium of the market" (WSF 2004).

Thabo Mbeki has famously stated that "poverty causes HIV-AIDS." However, if he were serious about addressing poverty as a causal factor of infection, he would have to increase government spending on social welfare and stop privatising basic services, including health care. The problem, however, is that this is impossible under the neo-liberal system that the South African government *voluntarily* adopted as a macro-economic strategy when it signed onto the World Trade Organisation (WTO) in 1994, and then in 1996, when the ANC adopted the Growth, Employment and Redistribution Macroeconomic Strategy (GEAR). It follows that its strategies to combat HIV-AIDS are constrained by the policy restructuring neo-liberalism requires.

In 2003, the Treatment Action Campaign pursued court action against two pharmaceutical companies. As a result of this court case, the cost of anti-retroviral (ARV) treatment was reduced, and the government was finally forced to adopt a National Treatment Plan that included a mass-scale roll-out of ARV medication. Despite this plan, the government has consistently attempted to undermine the roll-out of anti-retroviral treatment. The government claims that its reluctance comes from a distrust of the efficacy and safety of ARVs and a desire to oppose the power the international pharmaceutical companies wield over 'Third World' countries.

However, increased efforts to privatise health care and cut state spending on social welfare reveal the extent to which South African primary health care model is profoundly influenced by neo-liberal stipulations. The government discourse on health care highlights *community* and *individual* responsibility.¹ The Department of Health now allocates tremendous resources for community home-based care and support group initiatives. In this way, the government is outsourcing health care by making civil society (traditional healers, NGOs, etc.), families and individuals responsible for its provision. Outsourcing care means that less money will be allocated to the public health system, placing the burden of care squarely on the shoulders of communities. Furthermore, this care is mostly palliative: it is not treatment that

¹ The "healthy lifestyle" campaign is one recent example of this.

will save peoples lives. Finally, this health care model privileges prevention programmes and individual responsibility over treatment and state responsibility.

The very controversial debates around HIV-AIDS taking place in the South African public sphere have contributed to the obstacles community-based organisations face in mobilising around issues of HIV-AIDS. Between the denialism of the President and the Minister of Health, the Zuma trial, the Dr. Rath scandal, and the vocal outcry of the Treatment Action Campaign (TAC), many community activists feel incapable of joining the struggle against HIV-AIDS without becoming involved in this political fray. In addition, for many community organisations these debates pose problems of legitimacy. There is a sense in which HIV-AIDS is the sole responsibility of certain NGOs (like the TAC), and this results in the perception that there is no need or desire for more widespread approaches to fighting the epidemic. Collaborative efforts between organisations have also been difficult to initiate or maintain.

This research project is the first step the APF is making to break the silence surrounding HIV-AIDS that has permeated our struggles thus far. The difficulties within HIV-AIDS activism we have just outlined have helped to shape this project; however, we have only begun the difficult and long process of working through them. We hope to continue to develop and work through these issues within our organisation and in collaboration with other social movements and community-based initiatives. Without the generous support and funding from Oxfam, we would never have had the opportunity to engage in such important work.

The Aims of this Research Report

The original aims of the project were:

- To understand how HIV-AIDS is affecting communities in which the APF is active;
- To understand how problems related to HIV-AIDS relate to other problems brought about by neo-liberalism, i.e. water and electricity cut-offs, the privatisation of health care, etc.
- To develop an APF approach to HIV-AIDS that begins with the needs of communities, and that links the issue of HIV-AIDS with our broader struggle against neo-liberalism;
- To develop capacity amongst a group of APF comrades to conduct research.



THE RESEARCH PROCESS & METHODOLOGY



This project represents the first initiative the APF has taken in focusing its attention specifically on HIV-AIDS and its impact on poor communities. This project began on the weekend of 16-17 July 2005, when the APF Research Subcommittee facilitated a workshop on HIV-AIDS. Approximately 55 APF members, representing 17 community affiliates, participated over the span of the 2 days. The need for such a workshop arose during regular meetings of the Research Subcommittee when members raised the concern that HIV-AIDS was something affecting us all yet something that the APF did not have an approach to. A small group was formed within the Subcommittee to focus on HIV-AIDS, and the workshop developed out of this initiative. Over time, members of this group collectively designed the workshop and prepared for it to take place. The workshop was also facilitated collectively by members of the Subcommittee.

This workshop provided a space within the APF to begin discussing important issues related to HIV-AIDS and access to health care. It covered the following topics:

- Neo-liberalism and HIV-AIDS: A Global and National Perspective;
- Basic HIV-AIDS Education;
- HIV-AIDS in Our Own Communities;
- The Way Forward: Developing an APF Approach to HIV-AIDS.

Since that initial workshop, our knowledge has grown and matured significantly. As a subcommittee, we read secondary source literature, educated ourselves about the disease and its devastating impact on communities throughout South Africa, and engaged in a series of discussions about how the disease has affected the APF in particular. These discussions and educational sessions eventually allowed us to articulate our interests and objectives in conducting a research project focused specifically on the relationship between neo-liberal economic restructuring, health care, and HIV-AIDS.

This project took the form of collective, participatory research project conducted by a group of activists from the APF Research Subcommittee. In October 2005, the committee held a two-day workshop in which interested members received basic research skills training and worked together in groups to design an overall research plan and an operational plan for its delivery.

It was agreed that the research would be conducted in two communities in which the APF is active through affiliates: Sol Plaatje/DRD and Phiri, Soweto. The committee members felt that a project, comparative in nature, would allow for generalisable results. These two communities were selected for a variety of reasons:

- Phiri, because it is situated in Soweto, it is better resourced in terms of access to clinics and NGOs, whereas Sol Plaatje, because of its geographical isolation suffers greater problems in terms of access to health resources;
- Sol Plaatje is an informal settlement, and Phiri is a township settlement;
- A large percentage of the residents of Sol Plaatje are recent migrants (and even immigrants) to the Johannesburg region, whereas a larger percentage of residents in Phiri have lived in Soweto for several generations;
- Because the project is focused on the relationship between access to basic services such as water and electricity and access to health care, it was important to select one site in which services have been privatised through the pre-paid water meter system (Phiri), and one site in which basic services have not been privatised, but in which

access to these services is still lacking (residents of Sol Plaatje utilise standpipes and have no source of electricity).

A second workshop was held on May 22, 2006 to finalise the research plan, to develop the research tools (questionnaire-based survey and focus groups), and to begin training a group of members of the APF Research Subcommittee to conduct the fieldwork. During this workshop, it was agreed that the project would employ the following research methods:

Secondary and Archival Research

Whereas targeted information about the two chosen research sites is lacking, this research project was informed by more general secondary source literature on the relationship between poverty and HIV infection and access to treatment, including newspaper articles, archives, research conducted by various NGOs and research institutes, and Department of Health resources.

Questionnaire-Based Household Survey

It was decided that the 200 questionnaires to be filled out in both Phiri and Sol Plaatje should be gathered from a representative sample of the population of these regions. Therefore, in Sol Plaatje participants were selected in a proportional sample based on the region (Section D versus Section E) and the type of housing in which they lived (double-story hostel, single-story hostel, shack). Participants were selected at random from a representational sample of different housing structures stretched throughout the entire Sol Plaatje region. In Phiri, the questionnaires were divided evenly throughout the four regions of Phiri. The researchers targeted every fifth household to ensure random sampling.

Researchers were active members of the APF Research Subcommittee, which means that many of the researchers were unfamiliar with the community in which they conducted research. However, 4-5 APF members who were living in the area also participated in order to help researchers navigate an unfamiliar environment and to ensure the proportional representation of the sample. It should be noted that for ethical reasons (see below), these APF members did not select the participants in the survey themselves.

Researchers worked in pairs to allow for proper recording of information, and to help bypass problems that might arise in terms of language (the likelihood that one of the researchers would speak the chosen language of the participant increased if there were two researchers present during the interview). Interviews with residents in Phiri and Sol Plaatje were conducted from 29 May to June 2, 2006.

Focus Group Discussion

Because there is very little information on the impact of HIV-AIDS in each of these communities, and because the questionnaire did not ask specific questions about participants' experiences with HIV-AIDS (see discussion of Ethics below), it was decided that a general focus group discussion would be held in each community. Stakeholders from various NGOs and clinics were invited to participate in this focus group discussion, as well as randomly selected residents from the community. One general focus group discussion was held in each community and covered a series of topics, including:

- Access to health resources;
- Environmental risks and hazards;
- Non-medical sources of healing available to the community (i.e. support groups, traditional and faith healing, etc.);
- Experiences of HIV-AIDS in the community in general, including questions about:
 - Stigma and discrimination;
 - Social grants;
 - Treatment options;
 - NGO resources;
 - Prevention campaigns.
- Relationship between basic service delivery and HIV-AIDS;
- The burden women face in providing or securing health care.

The focus group discussions took place at the Phiri Library on 8 June 2006 and the Sol Plaatje Community Hall on 10 June, 2006. The discussions were facilitated by APF Research Subcommittee members, and were recorded and typed up for collective analysis in the final workshop (see below).

Participant Observation

General observations of the researchers conducting the focus group discussions and survey research were also recorded as a source of information, as were discussions held in the various workshops and committee meetings prior to the fieldwork itself.

The final analysis of the report was elaborated collectively, during a three-day workshop, by the members of the APF Research Subcommittee and the researchers from the Phiri and DRD communities who had participated in the fieldwork. The workshop took place on 25-27 August 2006 in the office of the APF in Braamfontein.

Research Questions

- How are individual members of communities experiencing HIV-AIDS?
- How are households experiencing HIV-AIDS?
- How are individuals and households coping with the problems related to HIV-AIDS?
- Do women experience HIV-AIDS in any specific ways in households and communities?
- Has HIV-AIDS had any effect on the relations between men and women in households and communities?
- Do problems with access to basic services have any impact on individuals and/or households dealing with HIV-AIDS?
- What mechanisms and/or institutions are there in communities to deal with problems related to HIV-AIDS?

Ethics

Because the topic of HIV-AIDS is a source of stigmatisation, discrimination and fear, the design of this research project included a coherent ethical procedure. This Ethics Procedure was the topic of debate in several meetings, and a coherent process was decided upon and agreed to during the May 22nd workshop. The goals of this process were to protect the participants from exploitation and ensure that their participation in the

research project would not put them in any danger (i.e. disclosure of HIV status, disclosure of decision to accept pre-paid system, etc.). The following measures were adopted in order to conduct the research with a proper ethical procedure:

1. Ethical design of the questionnaire:

It was decided that the survey would not ask participants to disclose their status, or to share their personal experiences with HIV-AIDS. Participants were only asked to respond to general questions about how HIV-AIDS affects their communities.

2. Ethical and equitable selection of participants:

It was decided that members of the APF who lived in the community in which the research was being conducted would not select participants for the survey research. Researchers from outside of the community would randomly select participants for the survey research.

3. Verbal Consent

Prior to giving the questionnaire, researchers were required to gain oral consent. The front page of each questionnaire contained the following script:

- a. All information provided will be kept confidential. You do not have to provide your name, and we only require your contact details in order to provide you with the final report;
- b. Your participation in this project is *voluntary*;
- c. You do not have to answer any question you are uncomfortable with;
- d. You can stop the interview/questionnaire at any time;
- e. You can ask questions throughout the process;
- f. You will not have to reveal anything about your own health status (unless you are comfortable with doing so);
- g. Do you consent to participating in this project?

4. Confidentiality Agreements

Each researcher signed a confidentiality agreement prior to conducting the research, which required researchers to agree that any information, including the identity of the participants interviewed, be treated as completely confidential and would remain confidential even after the termination of the APF research project. As such, each researcher agreed not to disclose any information of a personal and confidential nature to any person, including (but not limited to) family, friends, and co-workers, without the specific consent of the individual to whom that information pertained.



RESEARCH FINDINGS



A Background to the Sol Plaatje Extension in Durban Roodepoort Deep (DRD)

The Sol Plaatje extension, in DRD, is divided in two sections: Section D and Section E, each numbering about 1,500 households, which were both surveyed in our research. (The Department of Housing calculated that the total number of households in Sol Plaatje is 2,600, but in fact this number does not cover all the families living in the settlement, as counted in the roll-book kept by the Mandelaville Crisis Committee [MCC], a community-based organisation affiliated to the APF.)

Section D is occupied by the community of Mandelaville. The history and background of this community are summarised in a dossier compiled by the MCC:

The community of Mandelaville occupied land in Diepkloof, Soweto, between 1976 and 2002. The site was originally a police station and a

drinking hall, which were vandalised during the 1976 student uprisings. Some Diepkloof residents were subsequently granted residential permits to dwell in the vandalized buildings and upgrade them. The settlements steadily grew throughout the late 1970s and 1980s, swelling to some 1,500 households after influx controls were lifted in the final days of Apartheid.

After the 1994 election, all of Mandelaville's residents – whether or not they held residence permits issued under Apartheid – were treated as unlawful occupiers of an informal settlement and were advised to register for RDP houses.

As early as 1998, representatives of the City of Johannesburg promised that the community would be relocated to formal housing. But instead the City eventually relocated the community to Durban Roodepoort Deep (DRD), a disused mine compound. Most of Mandelaville's residents are still living on the new site, known as Sol Plaatje.

Well in advance of the relocation it became clear that DRD was not the formal housing that the Mandelaville's residents had been promised for well over two years. In addition, the community knew that DRD's (Sol Plaatje's) distance from schools, clinics and other essential social services would create considerable hardship after relocation.

The relocation was therefore highly contested. The community was evicted by court order. The relocation took place on 7th January 2002. (Mandelaville Crisis Committee: 3-4)

The court order stated that the City Council had 12 months from the date of the eviction to provide RDP (Reconstruction and Development Programme) houses to the Mandelaville community members. In 2003, a court case against the City Council was filed by the community: they demanded the RDP houses that they were promised in the court order used to evict it. To this date there are still no RDP houses – except 2 that have recently been built “for show” – in DRD.

The other section of the Sol Plaatje extension, Section E, was also occupied by people who were originally relocated, in 1999, from Maraisburg, South

West of Johannesburg. It is important to note, in this context, the significant differences in the history and background of the two communities, which mainly originate from the fact that the people from Section E agreed to leave their previous settlement, and, differently from the people living in Section D, did not fight against the relocation.

These different histories have had a significant impact on the relationship between the two communities, as is highlighted by the comments about the people who live in section E by a member of the Mandelaville Crisis Committee:

They were also relocated, and moved to DRD. But those people voluntarily wanted to be removed to DRD. The backgrounds and struggles of the people in Section D and E are very different. They agreed to anything the authorities suggested – unlike Mandelaville. But we are now trying to build links between us.

Before we moved into Sol Plaatje there was no transport, no taxis, no school transport, nothing. We managed to do that by mobilising, but before we came there was no mobilisation by the people living here.

Notwithstanding these different approaches to relocation, however, today sections D and E share the same living conditions. These are described in the dossier mentioned above:

Most people in Mandelaville live in shacks erected after the relocation. The rest live in old miners' hostels (Sol Plaatje). There is no electricity available on site. Water is drawn from taps in the hostels or from standpipes scattered throughout the settlement. Mandelaville is bounded by forest and mine-slag dumps on one side and by mine buildings, sinkholes and heavily polluted ground on the other. It is 5km from the main arterial route to Roodepoort and 35 km to Johannesburg. (Mandelaville Crisis Committee: 4)

The two sections of Sol Plaatje also share the same condition of extreme poverty and deprivation. A recent social survey conducted by the Centre for Applied Legal Studies at the University of the Witwatersrand found that “the unemployment rate in Sol Plaatje is 41%.” Those considered “employed”

include people earning a living in the informal sector. If informal sector employment is discounted, Sol Plaatje's unemployment rate rises to 56%. The study also calculated that "the mean monthly income per household was R851." "However," the study adds, "this figure masks significant inequalities" *within* the community:

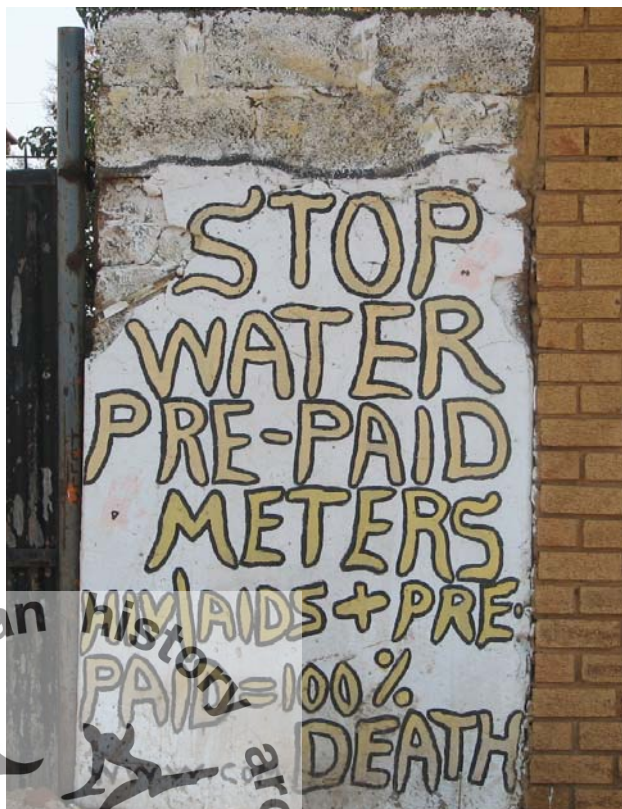
The poorest respondent subsisted on R100 per month, while the highest earning household reported an income of R9,180 per month. [...] Households in the lowest quartile received less than R370 per month. Top quartile households received more than R990 per month. These measurements place the great majority of households in Sol Plaatje in the bottom third of South African households ranked by income (Wilson 2003: 5).



A Background to Phiri, Soweto

Phiri is a township located in greater Soweto and bordered by Mapetla and Moroka. It was established in 1957 by the apartheid state. There are 1620 households in Phiri and Phiri extension.

The history of Phiri runs parallel to the history of the development in Soweto as a whole, but, compared by other areas in the township, it has long been distinguished by its population density. This is shown by recent report compiled by the Coalition Against Water Privatisation:



Between 1954 and 1969 the council built 50,000 low cost homes, most without inside bathrooms or toilets. No further state houses were built although banks started lending for middle class housing areas in the 1980s. In the 1970s most of Soweto was electrified, by the 1980s backyard shacks had to be built by residents because of the housing shortage. By the late 1990s Phiri had 1,963 backyard dwellings – almost one on every stand. [...] Phiri is exceptional even by Soweto standards: it has a population density of 181 persons per hectare, almost twice as dense as Chiawelo, Senaone and Moletsane – nearby sub-areas. (Coalition Against Water Privatisation: 11)

It must be noted, however, that in recent years several families have been relocated to Braamfischerville, another area of Soweto, leaving homes previously occupied by two families now with just one family.

As our findings illustrate, Phiri also shares with the rest of Soweto the prevalent socio-economic conditions, which are marked by a high rate of

unemployment and low income. It is noteworthy, finally, that this area was selected by Johannesburg Water to launch their campaign to impose water prepayment: in 2003 installation of prepaid water meters began in Phiri as the pilot project of a general installation of these meters in Soweto.

The Phiri Concerned Residents Forum (PCRf), which is affiliated to the APF, was formed at that time to resist the installation of these metres. While Johannesburg Water claimed that in accordance with the principles of participatory democracy, the Phiri community was consulted in relation to the installation of these metres, this was disputed by the PCRf, which held that prepaid water metres had been forced upon Phiri residents. The prepaid water metres were introduced by Johannesburg Water with the allowance of 6000 kilolitres of free water per household. The PCRf questioned that this is enough to meet the needs of Phiri households, and claimed that the metres would reduce water consumption to a level below that necessary to live a decent life.



Survey Results: Sol Plaatje Extension, Durban Roodepoort Deep (DRD)



General Profile of Respondents and Households

A total of 202 interviews were conducted with residents of the Sol Plaatje extension, DRD, using the collectively developed questionnaire. We interviewed a member of each of the households we surveyed, which represent 6.7% of the total number of households in Sol Plaatje. The overwhelming majority of the respondents, 72%, were women. The number of unemployed was also extremely high, 86%, to which we must add 6% students, while only 5% identified themselves as employed, and another 3% of the interviewees said that they were self-employed.

The composition of our sample, which in the case of the percentage of unemployed shows a higher ratio than available statistics on the community (see Wilson 2003:5), was influenced by the fact that interviews were conducted during the morning and early afternoon, when people in formal employment are away from home. Also, the high percentage of unemployment among women partly explains the over-representation of female respondents in our survey. Women are also more likely to carry the

burden of household tasks and tending to family and community needs. In fact, many of the men who were approached during the survey referred us to the women in the household saying that women “know everything about the house.”

Type of Accommodation and Household Size

Of the community members that were interviewed, 60% live in hostels' rooms, and 40% in shacks, all providing accommodation for 1 family of up to 10 members. All the people interviewed have lived in DRD for 7 years or less. This is due to the fact that DRD is a recent settlement where people have settled after they were evicted or relocated from other areas. As stated in the Background Section of this report, people in Section D were evicted from Mandelaville, in Soweto, in 2002, while people in Section E were relocated from Maraisburg, South West of Johannesburg, in 1999.

Socio-Economic Profile of the Household

The findings of our research confirm that the Mandelaville community in Sol Plaatje is among the poorest in the Gauteng region. 82.5% of the respondents said that their family lives on less than R1,000 per month, and no respondent's family has an aggregate income of more than R3,000. There are then pockets of even more extreme poverty: 12% of the respondents reported that their family has no source of income, and a staggering 55.5% said that their families live on less than R500 per month. Sources of income include grants and pensions (99 mentions), salaries (77 mentions), money sent by relatives (16 mentions) and sub-renting (3 mentions).

These statistics only partially reveal the appalling conditions in which the residents of DRD live. Despite the fact that the researchers who conducted this fieldwork are community activists from some of the poorest regions surrounding Johannesburg, they found the conditions in DRD truly shocking: “People in DRD are really struggling, they have nothing;” “I was really surprised, as an outsider. I have never seen anything this bad.”

Table 1: Monthly household income

	N	%
No income	20	12%
Below R 200	28	17%
R 200-500	44	26,5%
R 500-1,000	45	27%
R1,000-1,500	10	6%
R1,500-2,000	11	7%
R2,000-2,500	7	4%
R2,500-3,000	1	0.5%
More than R3,000	0	
Blank	36	
Total	202	
Total N counted (minus blank)	166	100%

Here is an excerpt from the field notes of one of the researchers:

I was in DRD on 2 June, 2006 doing research. I met an old woman. She was staying in a double-story hostel in Section E. When I talked to her, she started crying because of the poverty she suffers from. She doesn't have access to any grants, or to food parcels. She is staying with her grandson of 7 years. Her daughter took a grant for this grandson, but the old woman does not know where her daughter is now.

She told me that she was getting food parcels from the social worker. At the given date, when she returned for the food, they told her that it had been cancelled because her grandson is receiving a Child Grant. She says that she is trying to talk to them, but they refuse to listen.

This *magogo* told me that she sleeps for many days without food. She is getting food from the crèche in the afternoons. She said that she goes to the dumping grounds to try to find clothes and food – for herself and her grandson. She says that she has got a cough that won't stop. She has tried treatment, but it doesn't stop.

Because of poverty, she said that she wants to kill herself.

Water, Electricity and Sanitation

In DRD no household has water or electricity connection. There are faucets in the hostels, while people living in shacks get water from communal standpipes. The alternative sources of energy are mainly paraffin and candles, and in some households people also use batteries, gas and coal.

Table 2: Alternative sources of energy²

	N	%
Paraffin	202	100%
Candles	202	100%
Gas	65	32%
Battery	18	9%
Coal	12	6%
Total	202	

Although these alternative sources are not as efficient as electricity, and some of them, such as paraffin, are notoriously dangerous because of their high inflammability and represent a health hazard (some of our researchers reported that they had to interrupt interviews because of the irritation to their eyes and throat caused by paraffin), their cost, as a comparison with the survey results in Phiri illustrates, is significantly higher than electricity. Whereas in Phiri most households' monthly expense on electricity is below R100, in DRD 73.5% of the people we interviewed said that their family spends more than R100 on these alternative sources, and 29% told us that their family spends in excess of R200. Given the average income of DRD's families, access to these alternative sources of energy represents a huge financial burden on them.

² Percentages do not add up to 100% because the respondents gave more than one answer to the question, i.e. they rely on more than one alternative source of energy.

Table 3: Monthly expenditure on alternative sources of energy

	N	%
R20-50	10	6%
R50-100	33	20%
R100-150	42	26%
R150-200	31	19%
Above R200	47	29%
Blank	39	
Total Total N counted (minus blank)	202 163	100%

In our focus group discussion it became clear that, along with poverty, the environmental problems of the settlement and its isolation (see next Section), and the lack of basic services impacts greatly on people's health and general living standards. "Most of the people who are sick cannot get to the toilet," said one participant, "so they use buckets, so those buckets make them sicker.... The toilets are dirty because there is no water. There are germs there." "The paraffin smoke is really bad for you – it destroys people's lungs – even worse for people infected with HIV-AIDS," another participant reported.

Nutrition

Even though a high percentage of the income of Sol Plaatje's families is spent on food, because of the extremely low average income, 157 respondents – 85% of those who answered this question – said that their families have to make do with less than R500 per month for food. This negatively affects their abilities to secure nutritious and healthy food. Further, only 25 (12%) said that they are able to maintain a fruit garden.

Environment and Location

As we have already noted, many of the problems faced by the people living in Sol Plaatje, which are linked to and aggravated by the prevalence of extreme poverty in the community, have to do with the location of the

settlement and the lack of basic social services both in the settlement itself and in the surrounding area.

DRD is a disused mining area. On either side of the community, there are old, abandoned mines. Therefore, the community is surrounded by dangerously large holes, into which many children from the community have fallen. When it rains the holes get filled with water. Children then use them as swimming holes, but over the years, many have drowned or have been bitten by snakes.

Another major problem is that the area is isolated and surrounded by fields with high grass. These fields are extremely dangerous because they offer a shelter to “thugs or criminals who use those grasses for raping children and women.” During the focus group discussion, we were told that women and children get systematically raped there, and because the police station is far-away and the area does not get regularly patrolled by police, women and children have little or no protection from violent assaults.

Also, women pointed out that because of the distance of the police station and the clinics – where in order to be able to denounce the rape they need to go to get a doctor to make a statement – often they do not denounce the rape because they cannot afford the cost of transport, or because 24 hours pass before they are able to go. “The clinics are too far,” one woman told us, “so, we just lose hope, and just say, well, I've been raped, that's it. We don't have money for transport to the clinics or the police station. So reporting rape is useless.”

Sewerage leakage is another extreme health hazard for the community. Though the community regularly reports the constant sewerage leakages into their shacks and hostels to the local councillor, nothing has been done about this very severe health risk. When we conducted our research we could see a stream produced by leakage flowing through the main street in the settlement, and children playing in the holes where the liquid was stagnating.

A further complaint during the focus group discussion was that it is very difficult to maintain the minimum hygienic standards for a healthy living. We have already mentioned the problems with sanitation due to the fact that

there are no water connections, and the safety risks caused by the lack of electricity connections. Another issue that was raised, and one to which the community in DRD has long been very sensitive, was the lack of “proper housing” and the small size of existing accommodation: “The houses are so small and if I get sick, then my uncle gets sick, and then my mother too,” was a typical comment made by one of the participants in the focus group discussion.

Health Care

Costs, especially transport, are a crucial factor that we need to consider when we assess the community’s access to basic healthcare.

If someone in the household gets sick people are most likely to make use of clinics (56.5% of respondents), followed by the traditional healer (15%), hospital (13%) and home based care (10%).

Table 4: Kinds of healthcare people are most likely to use³

	N	%
Local clinic	114	56.5%
Traditional healer	30	15%
Hospital	26	13%
Home based care	21	10%
Social worker	9	4.5%
Other	3	1.5%
Total	202	

The main problems with access to health care for people living in DRD are related to the distance of clinics and hospitals from the settlement and the cost of transport. The closest clinics are: in Dobsonville, which is reachable in 30 minutes by minibuis taxi at a cost of R8 for a roundtrip; and the Discoverer’s clinic, which is reachable in 1 hour by minibus taxi or train at a

³ As in the table 2 the number of answers is in excess of the number of people interviewed because respondents could give more than one answer to the question. However, the discrepancy in this case is minimal. Only one person gave more than one answer.

cost of R15 for a roundtrip. The closest hospital is The Chris Hani Baragwanath Hospital, in Soweto, which is reachable in 2 hours by minibus taxi at a cost of R16 for a roundtrip. Participants in the focus group discussion reported that sometimes people do not have the R8 for transport to get to the closest clinic, or they are unwilling to spend the sum if they are not sure whether their condition is serious. This obviously affects both the provision of healthcare to the community and, in particular, the prevention of illness.

Because of the isolation of the community, ambulances take a long time to come to DRD. On the day when we conducted the focus group discussion, in the early afternoon, we were reported that one family had called the ambulance in the morning for someone who was sick, but the only ambulance in the area was busy, so the family was told to find an alternative means of transport. "Many people die before they get to the clinic or hospital," one participant remarked.

The quality of provision of health seems to vary between the various providers. Among the local clinics, participants in the focus group discussion agreed that one of the clinics, Discoverer's, offers a better service than the others, while the clinic at Leratong was described as "horrible." The complaints about this clinic ranged from the treatment of patients – "They don't treat people right," was one remark – to the fact that it takes a long time to get assistance and often people are discharged even though they are ill: "The ambulance just drops you there in the queue, and you sit there in the chairs, it will take a long time before you get assistance."

HIV-AIDS

Researchers observed and were told that there are a lot of "sick people" living in Sol Plaatje, but in our interviews we did not ask respondents to reveal their own or their relatives' HIV-AIDS status, even though a small minority told us that in their household there are positive individuals. We only asked a general question about health.

Most people did not disclose their status, but all evidence (from participant observation, interviews and the focus group discussion) suggests that the pandemic is having a major impact in the area. One of the researchers

reported: "One person said to me: 'Everyone in DRD will be HIV positive by 2010'."

Among the indicators that suggest the impact of HIV-AIDS on the community, respondents highlighted, in particular, the increase in illnesses, the need to care for the sick, increase in unemployment and the increase in number of deaths. However, detailed information is hard to come by because, as the questionnaire shows, it is difficult for people to reveal their status: when asked whether it is easy for people living in DRD to reveal their status, 155 respondents (76.5%) said that it is not. This is related to the problem of stigma, which is a very controversial and divisive issue in this community.

This was confirmed by the focus group discussion. Most participants highlighted that it is indeed difficult to disclose one's status because of the various forms of gossip, abuse and discrimination HIV positive people are subjected to, but others, especially NGO members, said that although stigma is undeniable, some people do disclose their status.⁴

The role of the NGO itself turned out to be controversial with respect to the issue of stigma and disclosure. Some of the participants in the focus group discussion in fact remarked that people had difficulties talking to NGO workers and volunteers because they are known to the community, and therefore, as one participant commented, "Since people get used to the NGO workers, they don't want to have them visit because it amounts to public disclosure." This remark prompted a defensive response from an NGO member, who stated that "The local NGO does use a strategy of privacy and confidentiality. It is just that the community is the one that is disclosing each other's status."

Gender is another pivotal element in relation to stigma. Women were very vocal during the discussion on this issue, and some reported that the simple request to the partner or husband to use a condom can be the cause of stigmatisation, with accusations ranging from being unfaithful to being

⁴ There is only one NGO in the community. It is called *Gugulesizwe*. The NGO goes house to house to attend to those who are sick, advises them of the treatment available to them and provides home based care. NGO personnel also give education on HIV-AIDS.

infertile. Women are also wary of going to clinics because they fear that if they are found HIV positive, the community will get to know about it and will marginalise them: “there is a stronger stigma for women who are infected,” we were told.

Another controversial and divisive issue turned out to be the role of traditional healers and sangomas. Ranked very lowly among the strategies to fight HIV-AIDS in the questionnaire answers (see Table 5 below), in the focus group discussion traditional healing was seen by some members of the community as “useful,” while many others expressed strong reservations and even overt suspicion towards traditional healers: “Sangomas cannot tell you how long you have been sick, and now, this is your status, and this is what you must do, and so on. Sangomas mostly they tell lies, they say you have been poisoned, and others will say your ancestor are punishing you. So, they don’t have a straight answer when it comes to HIV-AIDS.” The professional and ethical integrity of sangomas was also questioned by some of the participants: “Sangomas charge R50 firstly, just for reading bones. Then for the cure, it’s R400-500. Sangomas charge based on how much you earn.”

These and similar kinds of division within the community seem to be caused by the fact that there is no platform or opportunity in the community itself to discuss issues such as stigma and discrimination or, more generally, about the effect of HIV-AIDS on the people living in Sol Plaatje. Lack of information and opportunities for discussion are evidenced by some of the answers respondents provided to key questions about strategies of prevention, care and treatment of HIV-AIDS. For instance, a significant number of respondents, 77 (39%), could not answer the question “What is the primary source of support available in your community for those infected with HIV-AIDS”; and an additional 6% (11 answers) said that there is no support. Among the main sources of support were indicated: home based care, 39 answers (20%); support groups, 32 answers (16%); Community Based Organisations/NGOs, 30 answers (15%).

Our questionnaire also asked respondents to rank different strategies in terms of their effectiveness in fighting HIV-AIDS. The resulting table indicates that people living in DRD rank distribution of condoms and education as the most effective way of combating HIV-AIDS. Less importance is given to the existing

institutions and campaigns that have been set up to confront the spreading of the virus and its effects.

Table 5: Most effective strategies in fighting HIV-AIDS⁵

	N
Distribution of condoms	103
ABC (abstain, be faithful, condomise)	89
Basic HIV-AIDS education	84
Support group	76
Home based care	66
Nutrition programs	54
Clinics' distribution of ARVS	44
Health care offered by hospitals and clinics	35
Treatment Action Campaign's struggle for treatment	27
Traditional healing	25

Difficulty in accessing grants was highlighted as another key problem in the focus group discussion. Some participants noted that because of this difficulty, together with the lack of basic services in the community, sometimes people who are HIV positive cannot afford the money to cover transport costs to get medications. Also, because of the difficulty with getting grants, people cannot afford the "nutritious food" that the present Health Minister, Manto Thsbalala Msimang, says is crucial to the prevention of HIV-AIDS: "How are people who are sick going to afford nutritious food, if they are not given grants?" The "social grant process needs to change," was the final comment of this part of our discussion.

It also became clear during our focus group discussion, that HIV-AIDS affects women and men in different ways, and that it also affects the relationship between them. Women are the main carers in the family and the community

⁵ Respondents were given a range of 1 to 10, with one being the most effective: in our analysis we added up the number of responses ranking 1 to 3

and are therefore those who play the central role in caring for the sick. This also means that when a woman gets sick she can no longer perform this task. One of the economic demands from women that emerged from the discussion was the demand that women get paid for the caring work they do in the community, work that is outsourced to them because of lack of basic service. As a participant passionately argued: "This is work. Real work." "I think that most of the people caring for the sick are women. So, they need to be paid up because they put so much time on this work caring for the sick. It's overtime," said another.

In sum, from whichever angle we approached the issue, in our questionnaire and focus group discussion it was clear that for people in DRD the struggle against HIV-AIDS is a struggle to access free basic services, for access to medicines and good quality treatment and health care, resources, grants, wages, to live in a healthy environment with decent sanitation and eat nutritious food. It is a struggle for a better quality of life than the one presently imposed on them by the prevalent conditions of extreme poverty and poor or non-existent service delivery.



Survey Results: Phiri, Soweto



General Profile of Respondents

A total of 203 households were surveyed in Phiri by conducting interviews, using the collectively developed questionnaire, with an individual member of each household. This number represents 13% of the households in Phiri and Phiri extension.

Almost two-thirds (65%) of those interviewed were women. The composition of our sample was also characterised by a high proportion of youth (42%), defined as being between the ages of 15 and 35 years old. The number of unemployed respondents was also high at 73%, while the percentage of respondents who identified themselves as being employed (14 %), was almost identical to the percentage of self-employed respondents (13%). The forms of income generation which those identified as self-employed engaged in – such as hawker, selling beers, selling vegetables or sewing for neighbours – were precarious, which indicates that the majority of the self employed in Phiri are “necessity” as opposed to “opportunity” entrepreneurs.

For the most part respondents were well-established residents with 64% of interviewees having lived in Phiri for over 20 years.

Type of Accommodation and Household Size

Almost three quarters of people interviewed, 73%, indicated that they live in a house which they own, whereas 19 % live in houses that they rent either from other people or from the government. Thirteen respondents stated that they live in shacks, with nine of them living in backyard shacks.

The majority of respondents, 74%, live in 4 room houses while one in ten, 11%, live in 2 room houses. 11% of respondents also indicated that there were backyard shacks on their stand. 59% of respondents reported that only one family lives on the stand, while 22 % stated that 2 families live on the stand, and 19 % that more than 2 families live on the stand. The average household size derived from our sample was six members per household.

Socio-Economic Profile of Households

Although the findings of our survey confirm that Phiri is a part of Soweto with high rates of unemployment and poverty, its community is comparatively less poor than Sol Plaatje's. Unlike Sol Plaatje, for instance, no person interviewed reported that the household has no source of income. Still, as the table below illustrates, the percentage of respondents stating that their family lives on less than R1,000 per month is extremely high at 43 %. While income levels are higher than those in Sol Plaatje they are still low, with only 9 % of households surviving on more than R3,000 per month.

Only 115 households (57% of surveyed households) obtain some income from salaries, while 51 households (25% of surveyed households) rely solely on some form of state provision (pensions or grants) for survival. If one adds to this number those households with no access to a regular salary, but which supplement the grants or pensions received with a precarious source of income (such as casual work, the forms of self-employment described above, money from relatives living outside of the household or rents from tenants) the number of households reliant on state provision increases to 71 (35 % of surveyed households). 17 of the surveyed households has no access to grants, pensions or salaries, but is purely dependant upon income derived from the less than secure sources listed above.

Table 1: Monthly Household Income

Estimated household monthly income	N	%
No income	0	0%
Below R200	4	2%
R200-R500	21	11%
R500-R1000	62	31%
R1000-R1500	46	24%
R1500-R2000	18	9%
R2000-2500	16	8%
R2500-R3000	11	6%
R3000-R3500	17	9%
Blank	8	
Total	203	
Total N Counted Excluding blanks	195	100%

Access to Electricity, Water and Sanitation

Most respondents in Phiri (199) said that they had household access to electricity. The vast majority (87%) of households enjoy access to electricity via the prepaid system, with 11% having access to normal metered electricity and one respondent claiming to access electricity via a bypassed meter. Only nine of the surveyed households in Phiri utilise alternative energy sources such as coal and paraffin. Although most households' monthly expenses on electricity are below or equal to R100 (74%), given the low level of monthly income in Phiri this constitutes a significant proportion of income for many households.

Table 2: Monthly Household Electricity Expenses

Amount spent on electricity per month	Number of respondents	%
R20-R50	72	40%
R50-100	61	34%
R100-R160	34	19%
R150-R200	11	6%
Above R200	2	1%
Blanks	23	
Total	203	
Total N counted excluding blanks	180	100%

Table 3: Monthly Household Water Expenses

Amount spent on water each month	N	%
Below R20	7	4%
R20-R50	107	67%
R50-R100	29	18.1%
R100-R150	14	9%
R150-R200	2	1.3%
Above R200	1	0.6%
Blanks	43	
Total	203	
Total N counted Excluding blanks	160	100%

As with electricity, the majority of respondents (201), reported that they had a water connection in their households. Most of these households (86%) access water via prepaid water metres, while 9% are connected to water through ordinary metres, with 8 households accessing water via standpipes outside their yards, and two households claiming to receive free water (possibly having bypassed the metres). The small number of households with standpipes reflects the fact that Phiri residents are given a choice by Johannesburg Water between prepaid metres and standpipes. Choosing the standpipe, however, amounts to cutting oneself off from proper sanitation, as flush toilets are only possible through the prepaid system. These eight households are thus probably faced with unhygienic conditions, which facilitate the spread of disease and are not conducive to a healthy lifestyle.

The vast majority of respondents, 67%, stated that their households spend R20 to R50 on water each month.

Nutrition

A large percentage of households' income is spent on food, with 24% of households spending R300 per month; 15% of households spending R400 per month; 14% of households spending R500; and 14% of households spending R600. Considering that 67% of households survive on R1,500 or less, the high proportion of income spent on food is apparent. 71% of those who answered the question said that their family has to live on less than R500 per month for food.

Only 12 interviewees stated that they have a food garden in their house, which may be due to the need to restrict water usage to the bare necessities as enforced by the prepaid water system.

Although a communal food garden exists in Phiri, only 41 respondents, or 20% of the total were aware of this, and it is only utilised by 7 households. This suggests that despite the need of Phiri residents for access to nutritious food, this community requirement is not being fulfilled by the communal food garden, at least in part due to lack of awareness of its existence. It is evident that community "buy in" to the garden has not occurred.

Despite the high rate of unemployment in Phiri, the relatively large households and the small amount of money that many families are able to allocate to nutritional needs, only 6 households out of the 203 surveyed (a mere 3%) have access to food parcels.

The above data indicates that the nutritional requirements for healthy living of the Phiri community are not being adequately met. In this context, it is clear that access to healthy and nutritious food must a priority for campaigns focusing on the impact of HIV-AIDS on the community.

Healthcare

The importance of access to quality healthcare for the Phiri community is strikingly illustrated by the fact that 110 respondents, or 54% of those questioned, stated that at least one person in their household suffered from some form of health problem during the period in which the survey was conducted.

While only 8 people informed our researchers that someone in their household was afflicted by HIV or AIDS, this should not be understood to indicate a low presence of HIV in Phiri. Rather, those who conducted the research suggested that it possibly shows either an unwillingness to test for HIV due to fear, or an unwillingness to reveal that someone in one's household is infected by HIV due to the stigma which is attached to this disease. As it was stated by many of the participants in the focus group discussion, people in Phiri "are afraid to disclose their status."

Access to healthcare is a problem for Phiri residents. It was reported in the focus group discussion that there is no local community clinic or mobile clinic in Phiri. Phiri residents utilise clinics in the adjacent areas of Senoane and Chiawelo, and it takes them 30 minutes to walk to each of these clinics. According to the participants in the focus group discussion, since the clinics are relatively far from Phiri, they cannot adequately perform all the functions of a local clinic, such as ensuring that community members are not compelled to utilise vehicular transport to obtain medical care. In particular, participants in the discussion highlighted the difficulties caused by distance in case of an emergency: " We have grandmothers and sisters who get injured over the weekend but they cannot get help because the clinics are far from them," "...if something happened to me there is no mobile clinic in Phiri."

These clinics are used by 80% of the total of the households surveyed in the event of someone in the household falling ill. This clearly reinforces the point that Phiri requires a local clinic. Chris Hani Baragwanath Hospital is also regularly utilised by 59 (29%) respondents, while only 10 respondents said that they rely on traditional healers. Social workers provide healthcare to only 4 respondents, while 11 respondents said that are treated by private doctors. None of those interviewed in Phiri referred to home based care as a source of health care.

Table 4: Cost of One Visit to the Health Service Normally Used

Amount in Rands	N	%
0	116	58%
8	34	17%
9	4	2%
10	4	2%
12	1	0.5%
14	1	0.5%
15	3	1.5%
16	2	1%
18	5	2%
20	8	4%
21	2	1%
25	1	0.5%
30	2	1%
34	1	0.5%
35	1	0.5%
36	1	0.5%
64	1	0.5%
120	1	0.5%
125	1	0.5%
130	5	2%
150	1	0.5%
193	1	0.5%
200	3	1.5%
250	1	0.5%
Blanks	3	
Total	203	
Total N Counted Excluding Blanks	200	100%

A further problem relating to access to healthcare that emerged from the focus group discussion was the cost of ambulance transport to Chris Hani Baragwanath Hospital. According to participants, the ambulance fee varies

between R150 and R260, and furthermore “if people are in debt to the ambulance company it will still come to the community – but only for an emergency.” Some participants also maintained that the ambulance usually takes an hour to arrive in Phiri.

Most respondents said that, apart from transport costs, healthcare costs are minimal, with 116 respondents (58%) of the total stating that the healthcare services which they use cost nothing.

NGOs

Our researchers only encountered one NGO that serves Phiri: it is called Siphima (Senoane, Phiri, Mapetla) G AIDS Project, and is based in the Senoane clinic. Some of their members participated in the focus group discussion, in which the role of NGOs was amply debated. Participants complained that there is no NGO in Phiri itself and some reported that they had tried to form an organisation, but could not get financial support. An NGO worker replied that the problem is that people in Phiri “don’t respond to the services available to them,” and therefore opening an NGO in the area would not improve the situation. An animated discussion followed, with local residents arguing that “NGOs are not accessible to people in Phiri,” and that people in Phiri, as a community, need their “own clinic and their own NGO.” NGO members insisted that the problem is that people in Phiri do not utilise the existing services.

HIV-AIDS

As previously mentioned, only 8 respondents stated that there was at least one of the members of their household who was HIV positive, even though respondents identified increases in illness and in the number of deaths as signalling that the Phiri community is directly affected by HIV-AIDS. This caution in revealing one’s status is in accordance with the data collected: 149 respondents (73%) said that they consider it difficult for HIV positive persons to publicly disclose their HIV status in Phiri. This is a strong indicator, which suggests that discrimination against HIV positive people is prevalent in Phiri. This is also confirmed by the fact that 137 respondents (67%) stated that

stigma against those infected with HIV-AIDS is common in the community.⁶ This was also confirmed by the focus group discussion.

The primary sources of information on HIV-AIDS identified by respondents were the media (136 responses), clinics (107 responses), schools (79 responses), social workers (19 responses), NGOs (8 responses) and the Treatment Action Campaign (7 responses). 4 interviewees did not identify any source of information. According to the respondents, the main kinds of information available in Phiri are information on prevention such as the ABC campaign (80 responses), and basic HIV education (95 responses). Treatment literature, with only 36 responses, seems to be less available, and the same applies to training on legal/constitutional rights for people living with HIV-AIDS, with only 27 responses.

A large majority of people surveyed, 147 (72%), did not answer when questioned as to the primary source of support available to those infected with HIV-AIDS in Phiri, and an additional 3 people said there is no support. This may either be due to lack of support provided to those infected with HIV-AIDS in Phiri, or due to lack of information about this support. The main sources of support identified were clinics, with 13 respondents, and support groups, with 24 respondents, while there were only 2 mentions of home based care as a source of support.

As mentioned in the Sol Plaatje Section of this report, the questionnaire asked respondents to rank different strategies in terms of their effectiveness in fighting HIV-AIDS. Those strategies that aim at preventing or rather minimising the spread of the disease, such as the ABC (112 responses), distribution of condoms (112 responses) and basic HIV-AIDS education (101 responses), received the most responses. Strategies focusing upon caring for those already infected such as home based care (45 responses), support groups (63 responses), nutrition programmes (29 responses), health care offered by hospitals and clinics (53 responses), and clinic distribution of ARVs (48 responses) received substantially fewer responses. This data suggests that the

⁶ Here we are using data from the questionnaire that we decided not to use in the DRD Section because, due to problems with the way data was captured, were not confident that the information was reliable.

Phiri community generally perceives preventative strategies as more effective in fighting HIV-AIDS than existing strategies of care and treatment.

Table 5: Table Showing the Perceived Effectiveness of Different Strategies in Fighting HIV-AIDS

	N
ABC	112
Distribution of Condoms	112
Basic HIV-AIDS Education	101
Home Based Care	45
Support Groups	63
Nutrition Programmes	29
Traditional Healing	19
Health Care Offered by Hospitals and Clinics	53
Clinics Distribution of ARVs	48
TAC Struggle for Treatment	18

The findings drawn from this table, relating to the Phiri community's perception of a lack of effectiveness of strategies of care and treatment, is reinforced by the fact that 97 people, or 55% of those who expressed an opinion, disagreed with the statement that "the services provided by the clinics and hospitals are effective in fighting HIV-AIDS." Most respondents – 110, or 67% of those who expressed an opinion – felt that the clinics and hospitals do not treat people with HIV-AIDS with respect and dignity. It is pertinent that the majority of respondents did not believe that public health care is of high quality. The majority of respondents – 102, or 58% of those who expressed an opinion on this issue – felt that people with HIV-AIDS do not have satisfactory access to medicine and treatment for health problems, and 171 respondents, 84% of the total sample, agreed that HIV-AIDS campaigns should focus more on treatment.

A key issue raised in the focus group discussion was access to grants. There was a consensus in the discussion that there is the need for more information to be provided to Phiri residents on how to access social grants: many

people who should receive these grants do not know that these grants are potentially available to them. Grants are difficult to access, participants complained. They provided the example of the Foster Care Grants: "The person who wishes to become the caregiver for an orphan must have the birth certificate of the child. A social worker has to come and visit the child, then you have to go to court, and then wait for the money. Then you might go through this whole process, and still not get the grant. It can take 2 or 3 years, and there's nothing in the meantime."

As in the focus group discussion in Sol Plaatje, the connection between poverty, lack of basic services and resources, and the effects of HIV-AIDS in the community was repeatedly highlighted. Participants in the discussion were angered, in particular, by the fact that HIV-AIDS grants were only available to those with a CD4 count of less than 200, and felt that this indicated a lack of concern by the government for those infect with HIV-AIDS.



CONCLUSIONS/RECOMMENDATIONS

The findings of our research clearly indicate that the struggle for access to basic services, economic resources, nutrition programs, good quality health care, transport and information is crucial, alongside a dramatic increase in ARV roll-out, to the success of any strategy aiming to contain the devastating effects that HIV-AIDS is having on poor communities in our region.



The connection between HIV-AIDS and poverty is very real, and there is an urgent need to dissociate this connection from both the denialist rhetoric and the championing of untested method of treatment that have too often characterised the South African government's discourse on HIV-AIDS. This also means a shift of emphasis from the recent government's sponsored education and awareness programs, which are working at making individuals accept moral responsibility for the spread of the disease, and concomitantly shift the focus onto individuals and families.

Within this context, this report can provide the opportunity for a broader discussion within the APF of the effects of HIV-AIDS on our communities, and also for developing a coherent approach to HIV-AIDS based on the awareness of our members of the issues at stake with the struggle against HIV-AIDS. Already, the project has helped to build our research capacity by allowing us to come together, over a long period of time, to begin learning about HIV-AIDS and work towards shaping a coherent approach to the pandemic. This approach, as we have already indicated, is based on the recognition of how the problems of access to basic services relate to the impact of HIV-AIDS on our communities.

It is clear after this survey, that there is an absolute necessity for the APF to do further work on this issue. Our research points to some of the areas where we should intervene. In our future research and campaigning, we must further investigate the role of organisations and groups that are working on HIV-AIDS in order to initiate a more sustained dialogue and, where possible, establish links with them. In particular, we must strengthen our relationship with civil society organisations that operate in the communities where the APF is organising around access to free basic services.

It would also be important, in this context, to further investigate the availability of forums within our communities where the issue of HIV-AIDS, and in particular the problem of stigma and discrimination, can be discussed. During the focus group discussions, participants said that access to information is a major problem for communities affected by HIV-AIDS, and both in DRD and Phiri it was noted that information is especially needed on social grants.

The current health minister has, notoriously, promoted a nutritious diet as an alternative to Anti Retroviral medication, i.e. as an effective means of treating HIV-AIDS. Our data indicates that in both Phiri and Sol Plaatje there is limited access to cheap or free nutritious food, yet little is being done to secure this access, and that which is being done is insufficient. Obtaining such access to healthy food both for those infected with HIV-AIDS as well as to ensure general health and well being of the community is an issue that the APF should campaign around.

Such campaign may possibly be linked to community projects such as the growing of food gardens or increasing awareness about already existing community gardens. The issue of the linkage between such projects and campaigns was extensively discussed in the last APF Annual General Meeting (AGM). The point was raised that projects relate to issues of social reproduction and gender. The culmination of this debate was the formation of the new post of a Campaigns and Projects coordinator within the organisation. The issue of what kinds of projects to engage in is posed by our findings on HIV-AIDS and nutrition. Another area around which the APF may campaign is obtaining access to quality healthcare.

As a next stage of our research and campaign, we propose to organise public meetings on this issue in collaboration with other groups, including the Treatment Action Campaign. These meetings do not need to take the form of focus groups, but can be organised as campaign discussions or activist forums, and should aim to initiate a debate on the different aspects involved with the struggle against HIV-AIDS. These meetings will also give us an opportunity to distribute the popular pamphlet based on this report within our communities.



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