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Lessons from the front: NGOs and the fight against HIV/AIDS in South Africa

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Abstract

More than a decade after HIV became established in South Africa's general population, the unity of purpose and commitment needed to limit and reverse the spread of infection is still lacking. Social leaders and "celebrities" are, with some notable exceptions such as Judge Edwin Cameron, unwilling to admit they are infected with HIV. The government argues for the importance of taking a broad view of the social contexts of the epidemic by embracing poverty, inequality and the legacy of Apartheid. Some large corporations are considering the consequences of the epidemic, but their attitude to it remains ambivalent. Echoing the history of the struggle against Apartheid, responsibility for dealing with HIV/AIDS is falling increasingly on society's NGO sector.

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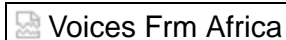
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Lessons From the Front: NGOs and the Fight Against HIV/AIDS in South Africa

by Brian Williams, Eleanor Gouws, Janet Frohlich, Catherine Campbell
and Catherine MacPhail

More than a decade after HIV became established in South Africa's general population, the unity of purpose and commitment needed to limit and reverse the spread of infection is still lacking. Social leaders and "celebrities" are, with some notable exceptions such as Judge Edwin Cameron, unwilling to admit they are infected with HIV. The government argues for the importance of taking a broad view of the social contexts of the epidemic by embracing poverty, inequality and the legacy of Apartheid. Some large corporations are considering the consequences of the epidemic, but their attitude to it remains ambivalent. Echoing the history of the struggle against Apartheid, responsibility for dealing with HIV/AIDS is falling increasingly on society's NGO sector.

South Africa has experienced successive epidemic waves of HIV/AIDS. The first was among gay men in the early 1980s, followed by infection among haemophiliacs through contaminated imported blood,¹ then among the heterosexual population, and now in babies of infected mothers.² Today about five million people are infected in the country. As the epidemic matures, up to one million people a year may die. By 2010 one million children will probably be orphaned by AIDS, and many of them will become feral children.

South Africa during the 1990s provided fertile ground for the spread of HIV. The epidemic became firmly entrenched as the social unrest and civil disorder that marked the dying years of Apartheid came to an end and Nelson Mandela was released from prison. Sexually transmitted infections (STIs) were barely managed in the black population, and the migrant labour system was still firmly in place. The advent of freedom of movement after the collapse of Apartheid meant that people, and so also diseases, could move about as never before. Given infection rates in neighbouring countries, it was inevitable that South Africa would be badly affected by the epidemic.

In 1994 there were an estimated 55,000 registered NGOs in South Africa.³ Foreign donors were needed to provide support for education, health and other social services not provided by the Apartheid government. NGOs specifically concerned with HIV/AIDS began to emerge in the late 1980s, and by 1997 more than 600 organizations were directly involved in HIV/AIDS. They developed educational programmes, provided care and counselling services, and created lobby groups calling for changes in legislation and arguing for the rights of people living with AIDS. To coordinate these efforts the National AIDS Convention of South Africa (NACOSA) was formed in 1990 to bring together government, the private sector, trade unions, political groups, AIDS activists and NGOs. They would work together to define principles and determine strategies for intervention.⁴ NACOSA was also given a mandate to develop a National AIDS Plan.

NGOs generally support a community-based approach to the epidemic that acknowledges the social

determinants and broader implications of HIV in prevention, care and support interventions. The Treatment Action Campaign has vigorously campaigned for access to treatment, including interventions to prevent vertical transmission of HIV. NGOs generally work with disadvantaged communities that are particularly vulnerable and susceptible to HIV, and are able to bring a sense of community ownership to a programme. They do this by employing community-based educators and carers and by establishing local reference groups or committees. They can create partnerships with the community, which can then determine the direction and nature of the project and influence the allocation and distribution of resources.

The NGO sector has achieved impressive results in many areas. By providing education and prevention programmes, community care and support, and advocacy and lobbying, they have helped inject a vision of non-discrimination, human rights and community participation into the national planning process.⁵ This work has been complemented by many community-based organizations (CBOs) including workplace groups and churches. Two community-based projects are examined below. One is in Hlabisa, a rural district in northern KwaZulu-Natal, which is the largest of South Africa's nine provinces. The other is in Carletonville, a major industrial centre in Gauteng. It is about 700 kilometers from Hlabisa, but linked to it by men who live in Hlabisa and migrate to Carletonville to work in the mines.

The Hlabisa Project

Hlabisa covers about 3,000 square kilometres and is home to some 215,000 predominantly Zulu-speaking people. Homesteads are widely scattered and people depend on subsistence farming, migrant labour and pensions. Hlabisa has a well-developed health service including a 430-bed hospital, 13 fixed primary health care clinics and a mobile clinic service. The South African Medical Research Council (MRC) has conducted research in the area since the early 1990s, and this has led to substantial improvements in community health care. In 1991 community-based, directly observed therapy (DOTS) was introduced⁶ using volunteers and community health workers who now manage 90% of tuberculosis patients.

The community of Hlabisa has benefited from research into community-based health care provision, but the epidemic continues unabated. Among women attending antenatal clinics in Hlabisa for the first time, HIV prevalence increased from 4.2% in 1992 to 14% in 1995⁷ and 34% in 1999.⁸ Over the same period, incidence among these women increased from 2.3% to 10% a year.⁹ Hlabisa has been identified as a potential site for prevention and vaccine trials, which should bring further benefits to the community.

There are many problems associated with working in rural areas such as Hlabisa. The homesteads in rural Zulu communities are widely scattered, and few people live in towns or villages. The hilly topography makes access very difficult, and roads are often poor or non-existent. The economy of South Africa is intimately bound up with what has come to be called circular migration, in which rural men and some women seek work in urban and industrial areas but retain the rural home to which they will eventually retire. At any one time more than 50% of adult men and up to 20% of adult women may be working outside the district in places as far away as Carletonville.¹⁰ A recent study of migration between Hlabisa and Carletonville¹¹ shows that HIV prevalence is higher among migrant men (28%) than non-migrant men (14%) but that in HIV-discordant couples the woman is as likely as the man to be the single infected partner. While migration increases the likelihood that men will be infected when away from their wives, it also increases the likelihood that wives will be infected while their husbands are away.

Rural society is highly complex and involves a range of cultural norms including attitudes toward polygamy, the importance of traditional forms of governance, and low levels of education. As a result of this diversity, scientists working on HIV/AIDS and related health issues in Hlabisa have developed good communications with the community. A community meeting was eventually hosted by the Inkosi (Chief) and his Izinduna (Counsellors) in Hlabisa in 1997. A Community Advisory Board (CAB) was

also elected by the community to promote partnership among researchers, research participants and community members.¹² Community educators, appointed by the CAB, were employed to raise awareness of HIV/AIDS among young people, encourage appropriate STI treatment-seeking behaviour, provide support for people living with HIV, prepare the community for participation in vaccine trials, and inform the community of research findings. Programmes for home-based and paediatric AIDS care were also introduced. In this way it has been possible to bridge the gap between the community and research workers and ensure that the rights and dignity of the community are protected.

The Carletonville Project

This project has been given the name *Mothusimpilo*, or “working-together-for-health.”¹³ It was set up to develop a sustainable community-based intervention and evaluate the impact on behaviour, sexually transmitted diseases and HIV in Carletonville, the biggest gold mining complex in the world. About 70,000 migrant mine workers, drawn from rural areas in South Africa and neighbouring countries, live in single sex hostels without their wives or families. In addition about 200,000 people live in the historically white town of Carletonville, the historically black township of Khutsong, and several smaller settlements in the area. The intervention was initially targeted at mine workers and sex workers since it was felt that they were at highest risk.

The intervention has two main aims: first, to ensure that all health services in the area—public, private and mine-based—provide state-of-the-art syndromic management of STIs while working closely with traditional healers; second, to develop effective and sustainable community-based peer education and condom distribution. Periodic presumptive treatment for women at high risk was subsequently added.

Efforts were also made to ensure that the main stakeholders were involved in the design, management and implementation of the project. In addition to the locally-based Carletonville AIDS Committee, these included the national and provincial departments of health, mine management and unions, various research organizations, and the principal donors. In this case these were the UK Department for International Development and the United States Agency for International Development.

A detailed series of evaluations was undertaken. Annual surveys are carried out in which blood and urine is tested for syphilis, gonorrhoea, chlamydia, HSV-2 and HIV. A detailed questionnaire covering a wide range of social, demographic, economic, biomedical and social issues is also administered.¹⁴

Unexpectedly, the first survey found extraordinarily high levels of HIV among young people, especially women, in the general population of Carletonville; about 50% of 24-year-old women were infected with HIV in 1998. The number is now closer to 70%. This dramatic and depressing finding led to a substantial change in the direction of the project, with much greater emphasis being placed on adolescents.

In many areas the project has been very successful. Women at high risk in what are locally known as hotspots (informal settlements close to mine shafts where alcohol and sex may be obtained) have developed an active and very effective programme of peer education. This has been extended to women at high risk living in Khutsong. Peer education among mine workers has been less successful, partly because the industry is unwilling to allow men time off work to be trained. Some of the schools in the area are developing their own AIDS programmes with the support of project staff. There is also an effective home-based care project running in Khutsong, but it remains short of funds and support.

HIV/AIDS in South Africa remains stigmatized, and many of the associated risk factors and problems including curable STIs, migration, poverty and gender violence are not adequately addressed. In spite of the evidence many senior political, business and other leaders either refuse to acknowledge the

impact that HIV/AIDS will have on society, or if they do, believe that their particular sector will weather the storm. At the same time extensive donor funding is available for HIV/AIDS programmes, interventions and research. International foundations, governments and drug companies have already committed up to one billion US dollars.

Many NGOs have achieved striking results with limited resources, but an epidemic of this scale cannot be effectively managed by NGOs. Rather, their role should be to provide links among communities, scientists, funding agencies and government. NGOs can explore and develop new ideas and new ways of dealing with the epidemic, and they will inevitably form a key component of a successful national strategy. However, without the support of others the good work that NGOs are doing will not be sufficient to turn the tide of the epidemic.


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