



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

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Policy Overview: HIV/AIDS Policy in South Africa

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

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

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

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

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

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*This Working Paper Series is dedicated to the memory of
Comfort Mfangavo
enthusiastic research partner in Dar es Salaam.*

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Working Paper 4

Policy Overview: HIV/AIDS Policy in South Africa

by

African Institute for Community-Driven Development

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GLOSSARY

ART	Anti Retroviral Therapy
ATTIC	Aids Training Testing and Information Centre
CBO	Community-Based Organisation
CCW	Community-Based Worker
CDW	Community Development Worker
CHW	Community Health Worker
CSOs	Civil Society Organisations
DFID	Department for International Development
DoA	Department of Agriculture
DoH	Department of Health
DOTS	Direct Observation Therapy Short-course
dplg	Department of Provincial and Local Government
DPSA	Department of Public Service and Administration
DSD	Department of Social Development
DWAF	Department of Water Affairs and Forestry
GDP	Gross Domestic Product
GEAR	Growth, Employment and Redistribution
HBC	Home Based Care
HPCA	Hospice Palliative Care Association of South Africa
IDP	Integrated Development Plan
MEC	Member of the Executive Council
MIG	Municipal Infrastructure Grant
NGO	Non-Governmental Organisation
NPO	Non-profit Organisation
OVC	Orphans and Vulnerable Children
PLWA	People Living With HIV/AIDS
RDP	Reconstruction and Development Programme
TB	Tuberculosis
VCT	Voluntary Counselling and Testing

EXECUTIVE SUMMARY

South Africa has the fifth highest prevalence of HIV in the world, with 29.5% of the population estimated to be infected. A combination of factors seem to be responsible for this, including: poverty and social instability; high levels of sexually transmitted infections; the low status of women; sexual violence; high mobility (particularly migrant labour); and lack of coherent policies. The government was also slow to react to the epidemic.

The government has a relatively solid policy framework to tackle AIDS, but the implementation encounters multiple political, infrastructural, and organisational problems. As a result, major activities in prevention, palliative and medical care, and research are carried out by nongovernmental agents, including a strong emphasis on the deployment of community-based organisations for the provision of home-based care.

Voluntary community and non-governmental responses to HIV/AIDS are diverse, such as self-help groups that respond to a particular need within their locality (community). Increasingly, such Community Care Workers (CCWs) or Volunteers are institutionalised through establishing policy guidelines for those involved in HBC. While many CCWs work largely on a voluntary basis, some CCWs receive the Departments of Health and Social Development stipend of R500 per month. However, there are no clear policy guidelines for the future career prospects for these CCWs. There is however a recent move toward harmonising the work of CCWs and the Department of Health has developed a Framework on Community Care Workers CCWs.

The involvement of People Living with HIV/AIDS (PLWA) in the formulation and implementation of services is encouraged. The involvement of beneficiaries of such services can strengthen and improve provider's attitude and understanding of issues affecting people living with HIV/AIDS. Wider benefits from involving PLWAs and OVCs include improved psychological and physical health, reduced isolation, better access to care and increased knowledge of HIV/AIDS.

A further policy consideration is that of care-givers. The government hopes that the newly installed system of Community Development Workers (see Working Paper 3) can support care-givers and signal problems.

Considering the inefficiency and contradictory nature of the government's AIDS policy and practice, HIV/AIDS activist organisations operating both on local and national level are crucial. However, the lack of government support and coordination has fed into conflicts over access to resources, conflicts of representational issues, and accusations of racism among both white and black groups within AIDS organisations.

1 INTRODUCTION

Southern Africa remains one of the regions worst-affected by the HIV/AIDS epidemic. A combination of factors seem to be responsible for this, including: poverty and social instability; high levels of sexually transmitted infections; the low status of women; sexual violence; high mobility (particularly migrant labour); and lack of coherent policies. The government was also slow to react to the epidemic.

South Africa has the fifth highest prevalence of HIV in the world, with 29.5% of the population estimated to be infected. The UNAIDS Global Report¹, estimated the number of AIDS related deaths in South Africa in 2003 ranged anywhere between 270 000 and 500 000. Given the numbers of people infected and dying, South Africa is regarded as having the most severe HIV epidemic in the world. This epidemic is still seven years away from peaking in terms of the numbers of projected AIDS related deaths.

Efforts to stem the tide of new infections have only had limited success, as behaviour change and social change are long-term processes, and the factors that predispose people to infection – such as poverty, illiteracy, and gender inequalities – cannot be addressed in the short term. Vulnerability to, and the impact, of the HIV/AIDS epidemic is proving to be most catastrophic at community and household level. Hundreds of people of all ages die in South Africa every day of AIDS related diseases. The hardship for those infected and their families begins long before they die, with the stigma related to suspected infection, the fear and despair that often follows diagnosis, the loss of income and support when a breadwinner or caregiver becomes ill, the diversion of household resources to provide care, the terrible burden upon family members, particularly children caring for terminally ill parents, and the trauma of bereavement and orphanhood. This all happens in a society where approximately 61% of South Africa's 18 million children live in poverty and 7.9 million people are unemployed (this equates to an unemployment rate of 40.9%). Obtaining accurate statistics on the number of children orphaned as a result of AIDS is problematic: if orphans are defined as children under the age of 17 whose mothers have died, UNAIDS² estimate 1,100 000 orphans due to AIDS were living in South Africa at the end of 2003. The other exacerbating factor is that for many years, the burden of care and support has fallen heavily on the shoulders of impoverished rural communities where sick family members return when they can no longer work or care for themselves.

Community-based care has been promoted as the best option by both government and civil society, since it is impossible to care properly for hundreds of thousands of people dying from AIDS in public hospitals. However, it is dangerous to assume that communities have limitless resilience and capacity to care for dying people and provide for those they leave behind. There is an acute need for social protection and interventions to support the most vulnerable members of the community and households affected by this epidemic. Women face a greater risk of HIV infection. In South Africa the infection rates between women and men is most pronounced in the age group: 15 -24 years whereby the infection ratio is 20 women for every 10 men. Young women tend to have partners who are much older than themselves, have other girlfriends and are more likely to be HIV infected. The South African Government's response

¹ Bradshaw D et al. (2004). Unabated rise in number of adult deaths in South Africa. *South African Medical Journal*, 94(4):278-279.

² UNAIDS. 2005. AIDS Epidemic update, December 2005

to the epidemic is grounded on the HIV/AIDS and STD Strategic Plan for the period 2000 – 2005³. The purpose of the plan is to provide a broad national framework around four priority areas: prevention; treatment, care and support; research, monitoring and evaluation; human and legal rights.

This came about as a result of considerable sustained pressure from advocacy groups who have been very vocal about HIV/AIDS related issues. Thereby forcing the government to adopt the Operational Plan for Comprehensive HIV and AIDS Treatment and Care in November 2003, this included the provision of antiretroviral (ARV) therapy in the public health sector⁴. The roll-out of the ARV programme is however proving a slow process. This is partly because the Department of Health needs to address major capacity and infrastructure constraints but also because it continues to broadcast confusing messages about the role of nutrition and traditional medicine, and the safety and efficacy of registered drugs that have been provided in the private sector for many years. By early 2005 approximately 30 000 patients were receiving ARV therapy through the state programme. The Operational Plan commits the government to provide ARV treatment to 1,650,000 people who need it by March 2008. The AIDS Foundation of South Africa recognises that the most effective avenue to support successful prevention efforts and secure access to effective, comprehensive treatment in vulnerable and marginalised sectors of society is to work in partnership with local community-based organisations (CBOs). The Foundation is a strong advocate of the view that communities should be participants in addressing their needs rather than objects of charity. Communities must be allowed to identify their own concerns and the responses that are feasible with the available resources.

Civil society organisations, particularly CBOs are well placed to play a strategic role in addressing the HIV/AIDS epidemic because of their close proximity to those affected. CBOs can draw on the support of committed community members, which is essential if interventions are to be affordable and sustainable. For this to happen, government needs to allocate more funding for community initiatives. While government policy supports the important role CBOs play in the fight against AIDS, the national and provincial AIDS programmes face many challenges in providing financial and technical support to these organisations. There are frequent delays in the approval and disbursement of funds; funding is usually only committed for a year at a time, with no guarantee for further funding; capacity building activities are often haphazard and are not built into a broader programme of ongoing monitoring and technical assistance. In addition, government and donor funding in South Africa is skewed in favour of national mass media programmes and scientific and academic research, with only a limited level of funding being directed at community driven responses to HIV/AIDS. There is a pressing need to scale up community interventions, for this is where the greatest degree of vulnerability exists and where the consequences of the epidemic are being most acutely felt.

2 THE SOUTH AFRICAN PICTURE OF THE HIV/AIDS EPIDEMIC

Recent estimates suggest that of all people living with HIV in the world, 6 out of every 10 men, 8 out of every 10 women, and 9 out of every 10 children are in Sub-Saharan Africa⁵.

³ HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 Department of Health May 2000

⁴ AIDS Foundation of South Africa. <http://www.aids.org.za/hiv.htm> 10 November 2005

⁵ UNAIDS. 2005. AIDS Epidemic update, December 2005

These figures provide sufficient evidence to make HIV/AIDS both a regional and a national priority.

The HIV epidemic in South Africa is one of the fastest growing epidemics in the world; Young women aged 20-30 have the highest prevalence rates; and young women under 20 years of age had the highest percentage increase compared to other age groups in 1998 and 1999 compared to 1997⁶. These and other data clearly indicate that the HIV epidemic is severely affecting the young, black, and economically poor populations of South Africa.

Currently there are approximately 3.5 million South Africans living with HIV. It is estimated that in 1998 over 1,600 people were infected with HIV each day – translating to more than 550,000 people infected each year⁷. It was estimated that by 2005, there will be 6 million South Africans infected with HIV and almost 1 million children under the age of 15 whose mothers will have died of AIDS. It is estimated that there were approximately 165,000 people living with AIDS and 120,000 AIDS deaths in 1998. Projections indicate that by 2002 a quarter of a million South Africans will have died of AIDS each year, and that this figure will rise to more than a million by 2008. Average life expectancy is expected to fall from approximately 60 years to 40 years between 1998 and 2008⁸.

Africa has the world's youngest population and estimates indicate that Sub-Saharan Africa is home to 70% of young people living with HIV/AIDS and 90% of AIDS orphans in the world. Literature studies indicate vulnerability to HIV/AIDS is compounded by gender and age, making young people, particularly young women more prone to contract the virus than others. The age distribution of HIV infection in Africa is skewed towards younger females, with infection rates among teenage girls five times higher than teenage boys in some countries.⁹

The Reproductive Health Research Unit of the University of the Witwatersrand conducted a study in 2003 on HIV and sexual behaviour among young South Africans, with specific reference to the 15-24 year olds. This reflected high levels of sexual activism amongst the youth, especially amongst males. The survey found that among 15-24 year old South Africans the HIV prevalence was 10.2%, with the incidence among women being higher (15.5%) than in men (4.8%). Among the 10% of South African youth who are HIV positive, 77% are women. The highest HIV prevalence was found in KwaZulu-Natal Province (14.1%) and the lowest in Limpopo Province (4.8%). In terms of geographic area, youth living in urban informal areas had the highest HIV prevalence (17.4%). More alarming is that 15% of young people who are often at greatest risk are not being reached by any HIV programmes. These include teenagers living on farms.¹⁰

On average, 67% of young people aged 15-24 years are reported to having had sexual intercourse. What is also significant about the findings is the fact that 6% of the interviewed youth reported having been forced to have sexual intercourse, which is 10% of females and 2% among males. Among the sexually experienced youth, 52% reported using a condom at last sexual encounter. Overall, among youth who reported having had sex in the past 12 months, females were significantly less likely than males to report always using a condom

⁶ UNAIDS. 2005. AIDS Epidemic update, December 2005

⁷ *ibid*

⁸ HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 Department of Health May 2000

⁹ Multisectoral responses to HIV/AIDS: A compendium of promising practices from Africa. USAID-PVO steering committee on Multisectoral approaches to HIV/AIDS, April 2003. P33.

¹⁰ HIV and sexual behaviour among young South Africans, 2004.

with their most recent partners (28% vs 39% respectively). Eighty seven percent of all youth sampled indicated that they were able to access condoms when they needed them. This clearly demonstrates that access to condoms does not guarantee/translate to condom use.¹¹

The 2002 Human Sciences Research Council/Nelson Mandela study in collaboration with the Medical Research Council and Centre for Aids Development, Research and Evaluation (CADRE) sampled more than 9000 South Africans in 2002 from all walks of life. Eleven percent of respondents were HIV positive and 15.2 % were between 15-49 years old. The results of the study indicated that 36% of the youth stated that they were at no risk of HIV infection compared to 14% who stated that they were at high risk. Among all youth, 60% indicated that they would like to be tested for HIV. Significantly, more females than males reported having been tested for HIV (25% vs 15%). From the findings of the study, the vast majority of young people agreed that safer sex is a shared responsibility between partners and that it is not acceptable to force someone to have sex. In addition, they also agreed that having many partners is not acceptable and it also not desirable to engage in transactional sex.¹²

The 1st South African National Youth Risk Behaviour Survey was conducted in 2002, and comprised of learners in Grade 8, 9 10 and 11 in public schools across all nine provinces. The survey looked at amongst other things, the percentage of learners who ever had sex; the age of initiation of sex; the number of sexual partners learner have had; use of alcohol or drugs before sex and the methods of contraception mostly used by learners.¹³ The study showed that heightened sexual awareness is part of adolescence development, but it is often characterised by experimentation which has the potential of placing adolescents at risk of unprotected sexual activity, unplanned pregnancy and sexually transmitted infections including HIV. In addition, the study shows that gender was found to be a predictor of condom use, with more males than females reporting having used condoms.¹⁴

A study undertaken by University of Cape Town (UCT) academics, Fiona Ross and Susan Levine found that most students at tertiary institutions continue to have unprotected sex despite being aware of HIV/AIDS and its dangers.¹⁵ The UCT study, based on interviews with 480 students between the ages of 19 and 30 found many students had unprotected sex despite being aware of HIV/AIDS transmission. The survey revealed that students imagine that they are immune to HIV infection and continue to practise unsafe sex.¹⁶ Reasons given to the researchers for this behaviour included: having gone too far without thinking, did not have condoms handy, being drunk, being in a long-term relationship and assuming it would be alright, among others. Furthermore, students also complained about HIV information fatigue. More positively, condom use was cited as socially acceptable.¹⁷ This point validates the findings of the 1st South African National Youth Risk Behaviour Survey in 2002, which also found condom use to be socially acceptable. While many young people are aware of the importance of using condoms, studies indicate that condoms whilst being socially acceptable, might not be necessary popular in usage.

¹¹ *idem*

¹² HSRC/Nelson Mandela study. 2002.

¹³ Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P53.

¹⁴ *Idem*, P51.

¹⁵ <http://www.iol.co.za/html/news/aids/index.php?caption> 10 November 2005.

¹⁶ *ibid.*

¹⁷ <http://www.iol.co.za/html/news/aids/index.php?caption> 10 November 2005.

2.1 Major causes and determinants of the epidemic in South Africa¹⁸

The immediate determinants of the epidemic include behavioural factors such as unprotected sexual intercourse and multiple sexual partners, and biological factors such as the high prevalence of sexually transmitted diseases. The underlying causes include socio-economic factors such as poverty, migrant labour, commercial sex workers, the low status of women, illiteracy, the lack of formal education, stigma and discrimination. The national HIV/AIDS & STD Strategic Plan must address all these immediate determinants and underlying causes.

2.2 Tuberculosis and HIV/AIDS¹⁹

Closely linked to the HIV/AIDS epidemic, is a Tuberculosis (TB) epidemic which is fuelled by HIV infection and which is also the most frequent cause of death in people living with HIV. In South Africa, approximately 40-50% of TB patients are infected with HIV. In some hospitals in South Africa, the HIV prevalence in TB patients has been recorded as over 70%.

3 CURRENT STRUCTURES IN SOUTH AFRICA TO ADDRESS HIV/AIDS²⁰

3.1 Cabinet

The cabinet is the highest political authority in the country, the cabinet prescribed that each government ministry have focal person and team responsible for the planning, budgeting, implementation and monitoring of HIV/AIDS interventions. The cabinet meets weekly but HIV/AIDS issues are not regularly discussed at this level as this has been deferred to the South African National AIDS Council (SANAC).

3.2 South African National AIDS Council

The South African National AIDS Council is the highest body that advises government on all matters relating to HIV/AIDS. Its major functions are to: (a) advise government on HIV/AIDS/STD policy, (b) advocate for the effective involvement of sectors and organisations in implementing programmes and strategies, (c) monitor the implementation of the Strategic Plan in all sectors of society, (d) create and strengthen partnerships for an expanded national response among all sectors, (e) mobilise resources for the implementation of the AIDS programmes, and (f) recommend appropriate research. This body is chaired by the Deputy President, and consists of 16 government representatives and 17 civil society representatives.

3.3 Interdepartmental Committees on AIDS

This committee consists of representatives from all government Departments who co-ordinate HIV/AIDS activities. The IDC meets monthly to review government programmes and to fulfil requests from SANAC. Goals of the IDC include facilitating the development of HIV/AIDS workplace policies in all Government Departments, ensuring that all Government Departments allocate financial resources to HIV/AIDS; and developing minimum HIV/AIDS programs for all Government Departments.

¹⁸ <http://www.iol.co.za/html/news/aids/index.php?caption> 10 November 2005.

¹⁹ *ibid*

²⁰ HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 Department of Health May 2000

3.4 MINMEC

The MinMEC consists of all Provincial Health Members of Executive Committees (MECs) and the national Minister of Health. The MinMEC meets every six weeks, and is the body that approves national policies and guidelines. HIV/AIDS is a standing item where reports on national and provincial programmes are discussed.

3.5 Provincial Health Restructuring Committee (PHRC)

This committee consists of all Provincial Heads of Health and meets on a monthly basis to discuss the strategic issues of national and provincial importance. HIV/AIDS is a standing agenda item where reports from the National HIV/AIDS/STD Directorate and Provincial HIV/AIDS Co-ordinators are discussed. Once the PHRC has discussed and approved documentation, it is referred to the MinMEC for the political approval.

3.6 Director- Generals Forum

This forum consists of Director Generals from all the National Government Departments and meets regularly. HIV/AIDS is a standing agenda item where reports from the IMC are discussed.

3.7 HIV/AIDS and STD Directorate Department of Health

HIV/AIDS issues are brought to the attention of the above national bodies by the Department of Health's Directorate of HIV/AIDS and STDs. This Directorate prepares briefing documents for these national forums, and attends meetings to provide further information to aid decision-making in these national committees and bodies.

To further enhance these structures, the Health Sector Strategic Framework (200-2005) asserts the need for an effective and efficient health information system for planning and managing health service delivery. Whilst some progress has been made in the last five years, progress must be accelerated during the next five years. It is imperative that health districts, municipalities, provinces, the private sector and the national department work together to build such an information system. In addition, various other government departments such as Home Affairs, Public Services and Administration and State Expenditure impact on the health system and must ensure that systems are integrated with those of the National Health department.

4 POLICY BACKGROUND

In 1985 the apartheid government repatriated Malawian mine workers who were suspected of being infected with HIV. Thereafter, debates around the AIDS policy were started, although the apartheid government had an HIV/AIDS policy, this policy lacked leadership, initiative and credibility.²¹ The challenge of HIV/AIDS facing South Africa became a struggle fought by labour unions, civil society movements, NGOs and CBOs. In 1991 the Congress of South African Trade Unions (COSATU) held a conference at NASREC to deliberate deeper on the AIDS issue. It was then that the Congress' first principled approach to HIV and AIDS was

²¹HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 Department of Health May 2000

adopted.²² However, the task of these organisations was made even more difficult in an era where there was neither a coherent national AIDS plan nor government funding. The National AIDS Congress of South Africa (NACOSA) is an initiative that was created in 1992 to bring government and the private sector to formulate a national AIDS Plan. The national AIDS plan bears the mark of the work, energy and vision of the non-profit organisation NPOs sector. The national AIDS plan was fully launched in 1994, but the implementation thereof by government is still making slow paced progress.²³

In 1997 the Ministry of Health headed by Minister Dr N C Dlamini Zuma tabled the White Paper on the Transformation of the Health System in South Africa²⁴, in parliament. The White paper on health deals with the transformation of the health services to reduce the large level of social inequality in health. The policies aim is to introduce a strong shift towards universal and free access to comprehensive health care, and change the disproportionate level of preventable diseases and premature deaths in certain segments of the population. A constant theme of the policy document is one of reallocation, and this is again evident in the call to shift resources from tertiary services in metropolitan areas towards overcoming the inadequacies of hospitals and clinics in rural areas. The White Paper recognises the importance of knowledge, information and evidence by stating that health research must be linked and integrated into planning, policies, programmes and implementation. The new National Health System would be based on a District Health System. Some of the principles behind this system of health care are equity, effectiveness, efficiency, accessibility and community participation. Each province will be subdivided into a number of functional health districts. The health district will serve both as a provider and purchaser of health services and select the most appropriate strategy on the basis of the principles set up above and an assessment of local conditions. However Zuma's policies failed to acknowledge the limited financial resources available to government, furthermore it seemed to be superficial theoretical exercise that was not informed by the institutional and social realities of South Africa. Dlamini- Zuma's tenure came under spotlight with the controversial government-sponsored AIDS play *Sarafina II*, there were allegations of cases of mismanagement of funds and misdirection by government in terms of dealing with the HIV/AIDS pandemic²⁵.

Over the same period the 1997 White Paper for Social Welfare began a departure from traditional welfare approaches, towards the provision of those services 'that would lead to more self-sufficiency and sustainability'. The Treasury argued that since a social service spending in South Africa is comparatively high, the problems of inadequate service delivery should be addressed by efficiency improvements.

Further, a 1997 Department of Public Service and Administration (DPSA) White Paper on Transforming Public Service Delivery promotes these efficiency improvements through a new framework of service delivery priorities. The emphasis is on 'a people must come first - customer concept', or "Batho Pele"²⁶. In 1998, the Local Government White Paper²⁷ made the legislative transition towards the notion of a "developmental local government", described as 'local government committed to working with citizens and groups within the community to find

²² Edwin Cameron, The principles of our progress in AIDS Bulletin, May/June 1997 vol 6.

²³ Barry Smith, AIDS hits everyone: HIV/AIDS and the NGOs in AIDS Bulletin, May/June 1997 vol 6

²⁴ White Paper for the Transformation of the Health System in South Africa. Department of Health - April 1997

²⁵ Butler, A. South Africa's HIV Policy, 1994-2004: How can it be explained? African Affairs 104/417, 591-614

²⁶ White Paper on Transforming Public Service delivery (Batho Pele). South African Department of Public Service and Administration. 18 September 1997

²⁷ White Paper on Local Government. South African Department of Local Government. 9 March 1998

sustainable ways to meet their social and economic and material needs and improve the quality of their lives'. Two pieces of legislation, the Municipal Structures Act (1998)²⁸ and the Municipal Systems Act (2000)²⁹, gave substance to this shift. The former provided for the establishment of ward committees to enhance a participatory democracy and women's participation. A range of provisions in the latter required that local government become the conduit for all forms of public and agency infrastructure and defined the role of communities in planning, service delivery and performance management. In so doing, objectives were set for attaining reciprocal rights and duties to become the vehicle over the next six years for the realisation of participation and consultation mandates, with the wards defined as the local constituency for representation and participation and consultation in planning and for service delivery.

These provisions precipitated an ambitious prioritisation of investment into developmental infrastructure, the associated delivery of services, and pro-poor support programmes, provided through most departments and a host of other public agencies. This period has thus been characterised by two predominant thrusts in pro-poor and anti-poverty social services spending. The first has seen increase in social security spending via a range of different grants and pensions. The second is the spending on 'development and job creation'. By far the greatest investment has been on the former, and recent broad-based estimates place the proportion at about 60/40 per cent.

Mechanisms for service provision vary across and within sectors. In principle if not always in practice, local government transformation has adopted many of the practices associated with transformation in local government worldwide, aimed at enhancing the legitimacy, effectiveness and efficiency of municipal service delivery. Entrepreneurship, facilitative partnerships, sustainable local development programmes, service delivery partnerships, internal trading entities, municipal business enterprises and companies, and local economic development partnerships, are just a number of potential arrangements and instruments either available or already adopted.

Despite efforts by government to bring service delivery to the people there seems to be an overemphasis on the delivery of physical infrastructure, failure to acknowledge the full human development potential present, and failing to ensure that the programme aligned its products to local needs and embedded itself into local institutions and economies.

Programme implementers at national level recognise that community development should occur through improvements in the general standards of living that flow from access to services. However since municipalities rather than communities were the instigators of community projects, the evaluation points out that there was in many instances a failure of communities to take ownership of assets. The recommendation was the beginning of a move to more demand-driven approaches for the programme, with projects being initially identified by communities themselves. The Ten Year Review also evaluated the effectiveness of the "people must come first - customer concept" embodied in the Batho Pele White Paper, which had emphasised consultation regarding specific levels of services, equality in access to services,

²⁸ Local Government: Municipal Structures Act Republic of South Africa [No 117 of 1998]

²⁹ Local Government: Municipal Systems Act [No. 32 of 2000]

accurate information about the services to be received, and of principles of apology, explanation and sufficient remedy in the event of non delivery.

The results were held as disappointing, with the “implementation of the policy not accompanied by cultural change programmes that address deep underlying issues, and the progress made tends to be superficial and the true determinants of service improvement have not been addressed resulting in diminishing returns on future efforts”. The review proposed deepening Batho Pele principles with reference to the Canadian Service Delivery Gap model contained in their Services First Programme. This emphasised knowing what citizens and clients expect in terms of public sector service, including how they want to be engaged and what their priorities are for service improvements; measuring progress in closing the service gap using a variety of tools, and ensuring accountability for results, improving the capacity of public organisations to provide the service that citizens expect, and using the appropriate mix of tools to help close the service gap.

Recommendations were based on incorporating the values of the state - a people-centredness similar to the notion of citizen-centredness in Canada, on governance, based on a notion of democratic rather than good governance - with its associated emphasis on public participation in decision-making, on performance management and accountability, and on the organisational redesign of government regarding appropriate internal and external partnerships with business, industry and CBOs, as well as the adoption of specific approaches to the design of public goods and services.

The magnitude of the need for HIV/AIDS related services became an issue that compelled all government departments, including the Ministries of Health and Social Development, to find and form partners with other service providers in order to complement government efforts. In 1998, the then Deputy President Mr Thabo Mbeki launched The Partnership Against AIDS which was aimed at mobilising all sectors in South Africa, including people living with HIV/AIDS, not only to raise awareness and understanding of the epidemic, but also to increase awareness of the rights of people living with AIDS. Furthermore the Partnership was set to encourage people who are HIV positive to disclose their status and to give a face to the epidemic.

Throughout this period a number of new policy legislation instruments were developed to reflect the Constitution. The Reconstruction and Development Programme (RDP)³⁰ of 1994, stresses the need for national government to be closer to the people it serves. It defines participation within a people-centred, rights-based mobilisation of communities, a people-driven process, with the role of the state not simply delivering goods and services to a passive citizenry, but stressing a growing empowerment and reliance on the energies of communities.

Voluntary community and non-governmental responses to HIV/AIDS are diverse, such as self-help groups that respond to a particular need within their locality (community). Indeed the Ministry of Health including, provincial departments of Health has already moved to formally recognise and institutionalise the role and position of some Community Care Workers(CCWs) or Volunteers by establishing policy guidelines for those involved in HBC. The guidelines are drawn from the South African National Guidelines on Home Based Care (HBC) in the Department of Health. HBC is an integral part of community-based care where the consumer can access services nearest to home at a level of comfort and quality to ensure a

³⁰ Reconstruction and Development White Paper, (Gazette 16085, Notice 1954), 23 November 1994

dignified death. HBC is viewed as a form of community care, which encourages participation by people who are able to respond to the needs of their communities. HBC aims to rekindle the traditional form of community life and foster a culture of responsibility amongst communities. The success of community care is dependant on the investment of resources, skills, time and energy by government, private institutions, and communities.³¹

Policy for community and HBC goes beyond assumptions that People Living with HIV/AIDS (PLWA) and orphans and vulnerable children (OVC) are passive recipients of care and support services. Their involvement in the formulation and implementation of services can enhance service delivery. The involvement of beneficiaries can strengthen and improve provider's attitude and understanding of issues affecting people living with HIV/AIDS. Wider benefits from involving PLWAs and OVCs include improved psychological and physical health, reduced isolation, better access to care and increased knowledge of HIV/AIDS. Therefore, with this base in polices, introducing the CCW model in the HIV/AIDS sector where PLWAs are involved can serve as a vehicle to build synergy for prevention, care and support initiatives to address HIV/AIDS.

While many CCWs work largely on a voluntary basis, some CCWs receive the Departments of Health and Social Development stipend of R500 per month. This however has yet to occur in all cases where CCWs are providing home-based care. In addition, there are no clear policy guidelines for the future career prospects for these CCWs. There is however a recent move toward harmonising the work of CCWs and the Department of Health has³² developed a Framework on Community Care Workers CCWs.

A further policy consideration is that of care-givers. Sound support systems need to be built as an integral part of HBC. Caring for a terminally HIV/AIDS patient is emotionally charging on the carer and their families. In most cases the relationship of care to patients extends beyond that of a routine task of providing home-care. Thus psychological support is crucial for the care-givers' mental health and prevents 'burn out'. This support can be provided through creating opportunities for care-givers to talk about their experiences in regular organised caregiver Forums or through linking care-givers with a psychologist or social worker for counselling sessions.

This went with a commitment to develop forms of institutionalised co-operation with civil society at local government levels, to ensure the system of ward committees functions in relation to legislation, as well as to deploy Community Development Workers (CDWs) in 21 identified urban and rural nodes by the end of 2004. In fact government policies for the roles and responsibilities of the CDWs have been in the making since 2002. In his State of the Nation address in February 2003, President Mbeki envisaged that: "...government will create a public service echelon of multi-skilled community development workers who will maintain direct contact with the people where these masses live. We are determined to ensure that government goes to the people so that we sharply improve the quality of the outcomes of public expenditures intended to raise the standards of living of our people. It is wrong that government should oblige people to come to government offices and have no means to pay for the transport to reach government offices".³³ The initiative is viewed as contributing to a

³¹ National Guideline on HBC and Community based Care, Department of Health, December 2001

³² National Guideline on HBC and Community based Care, Department of Health, December 2001

³³ National Policy Framework for Community Development Workers in South Africa: Discussion Document, Department of Provincial and Local Government, not dated

removal of the 'development deadlock', strengthening the 'democratic social contract', advocating for an organised voice for the poor and improving the government - community network, contributing to 'joined up' government.

Community Development Workers within this model are defined as "community-based resource persons who collaborate with other cadres to help fellow community members to obtain information and resources from service providers with the aim of learning how to progressively meet their needs, achieve goals and realise their aspirations and maintain well being. They are participatory change agents working within communities from where they are elected, where they live and to whom they are answerable for their activities. They are to be supported financially and functionally by a range of government spheres and departments, particularly local government. Although specifically trained and certified for their role, they have a shorter training than professional development workers who receive tertiary education. Professional development workers unlike CDWs are resident in the communities in which they work."³⁴

The programme is nationally driven and co-ordinated by the Department of Public Service and Administration (DPSA) and the Department of Provincial and Local Government (dplg), supported by provincial departments of local government, located in municipalities, with the locus of CDWs operation being the ward. The rollout is presently proceeding apace across different provinces at different rates.

5 INVOLVEMENT OF THE NON PROFIT SECTOR

The term non-profit organisation (NPO) embraces a variety of organisations and forms. It is made up of a number of organisations ranging from small and informal to big and organised organisations. The Non-Profit Act (1997) defines the term "non-profit" organisation as a collective of people who come together for a common purpose and agree to formalise a programme to fulfil this purpose. They conduct their activities towards this purpose and should there be excess income after expenditure (profit) this excess is made available to the benefit of the purpose. Non-profit organisations are known by other generic titles such as non-governmental organisation (NGO), community based organisation (CBO) civil society organisation (CSO), public benefit organisation (PBO), trust of foundation, charity and religious body or institution (also referred to as Faith Based Organisations - FBOs).³⁵

The involvement of the non-governmental sector in South Africa began in 1985 when the apartheid government repatriated Malawian mine workers who were suspected of being infected with HIV. Thereafter, debates around the AIDS policy were started. Although the apartheid government had an HIV/AIDS policy, this policy lacked leadership, initiative and credibility.³⁶ The challenge of HIV/AIDS facing South Africa became a struggle fought by labour unions, civil society movements, NGOs and CBOs. In an era where there was no coherent national AIDS plan and government funding. Voluntary community and non-governmental responses to HIV/AIDS are diverse, ranging from self-help groups that respond to a particular need within their locality (community). Non-profit organisations proved to be in touch with the social challenges that face people at grass roots level. However, they were faced with numerous problems, the key of which is the lack of adequate funding. In this

³⁴ *idem*

³⁵ The Non-Profit Act (Act 71 of 1997).

³⁶ *ibid.*

regard some NPOs struggled to integrate HIV/AIDS programmes into their development programmes. Moreover, disparity exists between established NGOs and CBOs with regard to the issue of allowances. On the one hand small CBOs struggle to keep their organisations afloat not to mention having the financial base to support CCWs. While on the other hand some NGOs have the expertise of professionals and the institutional capacity and long history of supporting CCWs, they also operate under a cloud of uncertainty of funding. Presently, there is no clear policy or legal framework in place to sustain or support the long term sustainability of these services.

Over the last few years many NPOs have increasingly come under the media spotlight with media reports highlighting widespread incompetence, chronic mismanagement and corruption in some NPOs. These are problems faced by NPOs across different sectors of service delivery. Results from a study commissioned by SAIH/INTERFUND in 1995, which was set out to investigate the capacity and feasibility of AIDS integration in the NPOs project revealed that the sector had a limited response to AIDS and there had been little consideration to how AIDS would impact on the organisation or target communities.³⁷ In addition, some communities in which NPOs were operating, AIDS was not necessarily perceived to be a priority, thus AIDS integration would imply imposing AIDS issues onto the community and that would in turn deem contrary to how NGOs tended to operate. The state awareness of AIDS was superficial and insufficient to integrate AIDS into organisational debates and activities. Most organisations were facing funding crises due to changing political paradigms and priorities, with many NPOs thus under constant threat of closure, with some becoming reluctant to take up new issues.³⁸

The non-profit organisations focused mainly on the marginalised and disadvantaged groups in South African society by developing programmes that address the particular needs of their target groups and drawing the links between ill health and discriminatory legislation. In 1992 a National AIDS Convention of South Africa (NACOSA) was established in 1992 and the new ANC government accepted its strategy for fighting AIDS in 1994. However, the response to HIV/AIDS was clouded in controversy, over issues such as the allocation of R14.3 million to a play about HIV/AIDS, and the refusal of the government to make HIV/AIDS the responsibility of the President's Office. The magnitude of the need for HIV/AIDS related services became an issue that compelled all government departments, including the Ministries of Health and Social Development, to find and form partners with other service providers in order to complement government efforts.

Since the late 1990s with the scourge of HIV/AIDS rising, the number of Non Profit Organisations NPOs/CBOs has grown at a phenomenal rate with many of them operating informally. The emergence of NPOs working with people living with HIV/AIDS signified an attempt to eradicate the failings of the government department's ability to address the HIV/AIDS epidemic. The inadequacy of the apartheid government to respond to the epidemic spelled out serious implications for the future of the country. The non-profit organisations focused mainly on the marginalised and disadvantaged groups in South African society by developing programmes that address the particular needs of their target groups and drawing the links between ill health and discriminatory legislation. In this way, the NPO sector began to address some of the pertinent issues associated with the epidemic in the context of the

³⁷ Nikki Schaay, The history and development of NGO-based HIV/AIDS work in South Africa, in AIDS Bulletin, May/June 1997 vol 6.

³⁸ idem

Third world.³⁹ The struggle was multifaceted in nature; there was the struggle of educating people about HIV/AIDS, prevention of the spread of HIV, combating ignorance, eradicating stigma and discrimination. The environment in which the struggle was conducted was often unsupportive and hostile, at the same time the HIV/AIDS epidemic was progressing from dream and nightmare to being a "plague", that is a felt reality.

It would seem no NGO/CBO can claim to have adequate resources. In fact, the numerous challenges faced by NGOs/CBOs are too big for the resources at the disposal of these organisations. Lack of government capacity in key departments such as DoSD and DoH has underlined the importance of NGOs/CBOs in serving the marginalised communities especially in rural communities. The magnitude of the need for HIV/AIDS related services alone compels all government departments, including the DoH and DoSD, to find and form partners with other service providers in order to complement government efforts.

An investigation into the creation of an enabling environment of non-profit organisations began in 1996 and culminated with the promulgation of the Non-Profit Organisations Act in 1997.⁴⁰ The Act came into operation on 1 September 1998 as a result of a lengthy process of policy and legislative reform negotiated between the state and NPOs. Primarily, the Act intends to establish a regulatory framework within which NPOs can conduct their affairs, while encouraging the maintenance of adequate standards of transparency, good governance and public accountability.⁴¹

6 EMERGENCE OF DOMINANT NON-PROFIT ORGANISATIONS

Outside the government sector, a number of comprehensive networks of civil society role players have dominated the contemporary HIV/AIDS politics in South Africa. Although there are countless organisations that have received national exposure and some degree of success in the HIV/AIDS arena, none have been more successful in pushing their agenda nationally and internationally than the Treatment Action Campaign (TAC). Since its inception in 1998, the TAC has demonstrated the resilience that was characteristic of many pre-apartheid struggle movements.

The TAC was established on 10 December 1998, International Human Rights Day and since then it has specifically targeted a number of pharmaceutical companies about their monopoly and high pricing policy on HIV drugs. The TAC's main objective has been to campaign for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments. The Constitutional battle about the improved access to HIV drugs with the South African Health Department ranks as one of the most celebrated achievements of the organisation. The Constitutional Court in July 2002 ruled in favour of TAC- that the government devise and implement within its available resources a comprehensive and co-ordinated programme to realise progressively the rights of pregnant women and their newborn children to have access to health services to combat mother-to-child transmission of HIV.

³⁹ idem

⁴⁰ <http://www.socdev.gov.za/About%20us/chron.htm>

⁴¹ idem

Subsequently, in November 2002 the South African Government announced plans to implement the operational ARV treatment plan.⁴²

Other organisations (although not an exhaustive list) that have also played prominent roles in bringing HIV/AIDS issues to the forefront on the national agenda include the AIDS Consortium and the National Association of People living with AIDS (NAPWA). The AIDS Consortium is a network of over 1000 member organisations, mainly CBOs focusing on HIV/AIDS related issues. The key objectives of the AIDS Consortium include amongst others, the need to build the capacity of member organisations with respect to information and to promote practical community-based HIV/AIDS response initiatives in conjunction with local communities, collaborative institutions, and local businesses.⁴³ The National Association of People Living was established in 1994 when a group of concerned people living with HIV/AIDS met in 1994 and decided to form a national organisation that co-ordinates the needs and resources of all people living with HIV/AIDS. NAPWA's membership is open to people infected and affected by HIV/AIDS and its major purpose is to organise, mobilise and empower people living with HIV/AIDS, and to represent their interests by providing care and support. NAPWA has a number of provincial offices and regional branches throughout the country⁴⁴.

More recently, the AIDS Consortium has come under increasingly pressure to address its administration after it was realised that the Consortium was facing a financial crisis. At the beginning of 2004 there were media reports that the Consortium administration was under investigation for mismanagement. A financial audit was commissioned and the Director who was on sick leave at the time was suspended so as to allow for an uninterrupted flow of the audit process.⁴⁵ The resolutions adopted following the audit report includes, seeking legal advice on how best to instigate disciplinary action against the Director and Finance Manager of the organisation, to make recommendations on future issues of governance, under legal advice, and in compliance with the governing documents of the organisations⁴⁶.

Over the last few years, the relationship among many NPOs in the HIV/AIDS sector have undergone very significant changes, and not for the better as many media reports would attest to. In March 2004, NAPWA was accused of verbally and physically attacking a member of the TAC in a monthly meeting of the AIDS consortium. It is alleged that some NAPWA members led a racist attack on a white member of the AIDS Consortium, who was told that "we are sick of white people sitting at the front of the meeting; it causes us pain." to the applause from NAPWA leaders. At the end of the meeting the national organiser of NAPWA, confronted a white TAC member and shouted in front of other people "we are sick of you fucking white racists taking advantage of black people and people with HIV/AIDS".⁴⁷ This infighting amongst prominent HIV/AIDS organisations may not necessarily benefit the broader struggle against HIV/AIDS. *For Zackie Achmat, Chairperson of the TAC, HIV/AIDS affects everyone in the country irrespective of race and gender.*⁴⁸

⁴² <http://www.tac.org.za/>

⁴³ <http://www.aidsconsortium.org.za/>

⁴⁴ <http://www.napwa.org.za/content/documents.html>

⁴⁵ The AIDS Consortium Newsletter Special audit edition, March 2004

⁴⁶ idem

⁴⁷ Mark Heywood. 2004. TAC & AIDS Consortium condemn the threats by NAPWA against AIDS activist. Available: www.equality.org.za/news/2004/04/02tacondems.php

⁴⁸ Zackie Achmat. 2004. The Treatment Action Campaign, HIV/AIDS and the government. Transformation Journal, Volume 54.

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