

"Anita"

Anushka Virahsawmy





# CHAPTER 7

## HIV and AIDS

### Article 27



Rose Thamae, in front, marches with the Treatment Action Campaign (TAC) in Pretoria South Africa as part of the TAC's civil disobedience campaign in April, 2003. *Photo: Lori Waselchuk*

#### KEY POINTS

- At 54% South Africa comes eighth in the SADC region using the SGDI score. This is one of the worst performing areas.
- Citizens however score the government 82%, which ranks the country at second place. This reflects the recent turn around and huge government investment in prevention, treatment and care.
- The infection rate overall is declining and now stands at 17%. Women constitute 59% of those infected.
- Over the last decade there has been a 27% reduction in deaths as a result of HIV and AIDS due to much higher uptake in Anti Retrovirals (ARVs).
- Care work is still an unpaid profession in South Africa.

**Table 7.1: SGDI and CSC scores on HIV and AIDS**

	SGDI	CSC
<b>Scores</b>	54%	82%
<b>Ranks</b>	8	2

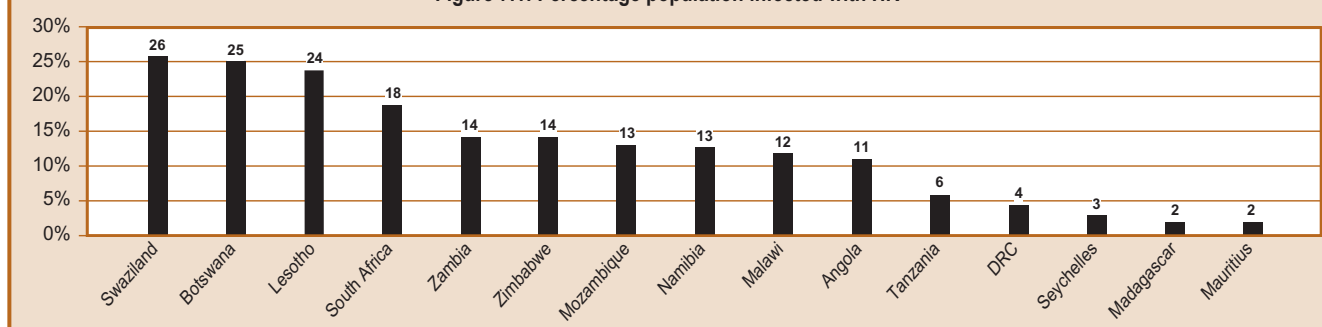
In spite of the government's recent turnaround on HIV and AIDS, this is one of the worst performing areas for South Africa. With a SADC Gender and Development Index (SGDI) score of 54% South Africa is eighth in the SADC region using this measure. The SGDI measures comprehensive knowledge on HIV and AIDS by women and men; the proportion of women who are HIV positive as a percentage of all people who are HIV-positive and HIV women receiving Prevention of Mother To Child Transmission (PMCTC) treatment as a percentage of all HIV positive pregnant women.

The Citizen Score Card (CSC) based on citizen perceptions places the country at a much higher 82%. This shows a high optimism among the population as a result of the measures being taken by the government. Some issues not captured by the SGDI but likely to influence citizen views are universal access to treatment, support and care for men and women living with HIV and AIDS.

### Background

HIV in South Africa is transmitted predominantly heterosexually between couples, with mother-to-child transmission being another main infection route. Drivers of the epidemic in South Africa are intergenerational sex, multiple concurrent partners, and low condom use, excessive use of alcohol and low rates of male circumcision.

**Figure 7.1: Percentage population infected with HIV**

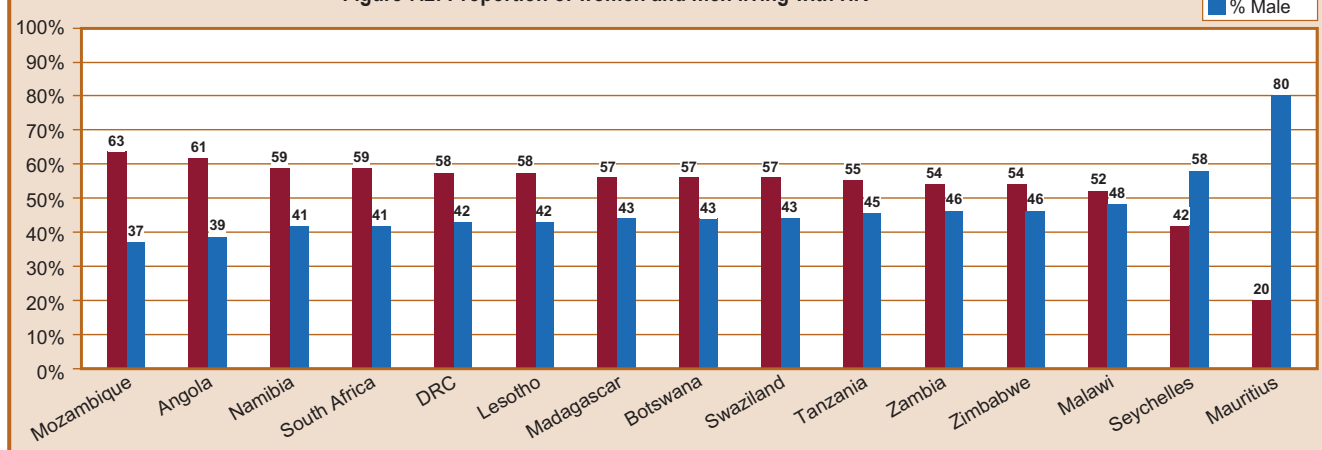


Source: SADC Gender Barometer, 2013.

Figure 7.1 shows that HIV and AIDS prevalence varies greatly in SADC countries. South Africa (18%) is among four of the 15 countries that have an HIV prevalence

rate of more than 15%. The highest prevalence is in Swaziland (26%); Botswana (25%), Lesotho (24%) and South Africa (18%) are also very high.

**Figure 7.2: Proportion of women and men living with HIV**



Source: UNAIDS 2012.

Figure 7.2 shows that a higher proportion of women than men live with HIV and AIDS in SADC except in Seychelles and Mauritius, where the virus has mainly

been transmitted through the needles of drug users, most of whom are men. The graph shows that 13 SADC countries have a greater proportion of females than

males living with HIV. Of the share of people with HIV in South Africa 59% are women placing the country at number four in the region.



Youths role playing during training HIV and AIDS training in South Africa, 2005. Photo: Trevor Davies

higher HIV prevalence among teenage males and females who reported having sexual partners who are five or more years older than they. Owing to unequal power dynamics in such relationships, vulnerability may be exacerbated for young girls who do not have the skills and power to negotiate condom use<sup>2</sup>.

The response to HIV and TB in South Africa falls under key number two of the Negotiated Service Delivery Agreements (NSDA) which is part of the 12 key outcomes of the government departmental mandates. The Social development department under its obligation to ensure "A long and healthy life for all South Africans" is focusing on addressing structural determinants (mobility and migration, gender roles and norms, sexual abuse and intimate partner violence and social safety-nets to address the impacts of the epidemic while Public Service and Administration focuses on the public service workforce and ensures adherence to public service guidelines<sup>3</sup>.

Some of the contributing factors that have exacerbated the HIV and AIDS prevalence are: lack of equal rights within marriage, the need for protection of women and girls from violence and abuse, and the need to strengthen education and awareness programmes to eliminate traditional and cultural practices that increase women's vulnerability to HIV and AIDS

In relation to intergenerational sex, research has identified younger females having sex with older males as an important factor contributing to the spread of HIV. Subsistence needs and materialism usually motivate such relationships<sup>1</sup>. Shisana and colleagues (2009) found

South Africa is facing a major and mounting financial challenge as it strives to respond to the HIV/AIDS epidemic in the country. The funding needed to respond to HIV/AIDS on three critical fronts - for prevention, treatment, and care of orphans and others affected by AIDS - is continuing to escalate rapidly, especially as hundreds of thousands of additional South Africans enter ART programmes. This situation poses huge financial dangers and risks for the country, particularly at a time when South Africa is feeling the negative effects of the global economic recession and is struggling to maintain its government budget for a wide range of pressing needs, beyond HIV and AIDS<sup>4</sup>.

## Prevention



*The Protocol requires that by 2015, state parties shall develop gender-sensitive strategies to prevent new infections, taking account of the unequal status of women, and in particular the vulnerability of the girl child as well as harmful practices and biological factors that result in women constituting the majority of those infected and affected by HIV and AIDS.*

<sup>1</sup> Shisana O, Rehle T, Simbayi LC, Parker W, Zuma K, Bhana A, Connolly C, Jooste S, Pillay V, et al. (2005) South African National HIV Prevalence, HIV incidence, Behaviour and Communication Survey, 2005.

<sup>2</sup> Parker W, Makhubhele B, Ntlabathi P, Connolly C. Concurrent Sexual Partnerships amongst young adults in South Africa. Challenges for HIV prevention communication. Challenges for HIV prevention communication. CADRE. 2007.

<sup>3</sup> Global AIDS response progress report 2012.

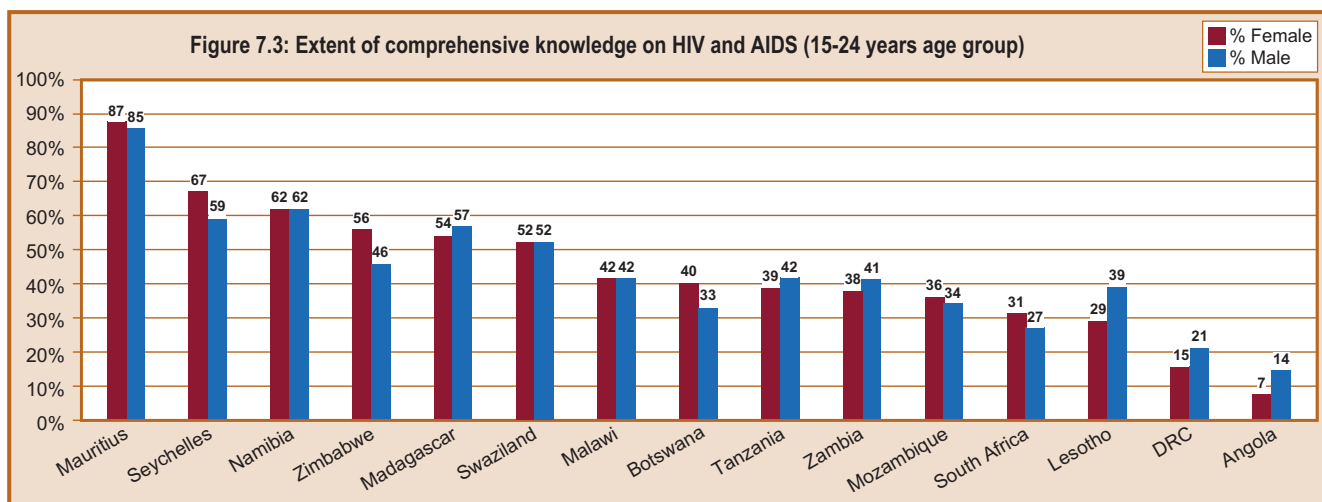
<sup>4</sup> CEGAA/Results for Development Institute, 2011, Costs and Financing of HIV, and AIDS in South Africa.

In South Africa, the wide delivery of effective behaviour change strategies has been central to reversing the global HIV epidemic, and has formed a key element of the national prevention pillar. The national approach to prevention recognises that human behaviour is complex; widespread behaviour changes are challenging to achieve; and that there are important gaps in knowledge about the effectiveness of HIV prevention.<sup>5</sup> The government and civil society have joined forces in rolling out HIV prevention activities from national to

local level to ensure that HIV becomes a natural and central topic of discussion, and that new societal norms are forged.

The South African National AIDS Council which is a multi-sectorial body providing high level leadership and co-ordination. The council is chaired by the deputy president of the country. The council consists of 8 government ministries and 18 civil society and private sector organisations.

### Public education and awareness



Source: World Health Organisation<sup>6</sup>.

Figure 7.3 shows that at 31% for women and 27% for men, South Africa, comes 12th with regard to comprehensive knowledge on HIV and AIDS. This demonstrates that the country still has a long way to go.

The government has identified the school system as an important entry point for scaling up public education and awareness on HIV and AIDS. The Department of Basic Education (DBE) has been strengthening the HIV and AIDS life skills education programme through activities like the review of the sexuality education curriculum against the United Nations Educational Scientific and Cultural Organisation (UNESCO) international guidelines on sexuality education; classroom observations of lessons; development of scripted lesson plans for educators and by conducting qualitative research to better understand factors that facilitate and inhibit the teaching of Life Orientation in schools.

There has also been a focus on capacity development, with 3 545 teachers trained as Master Trainers, and 24 275 teachers capacitated from January 2010 to December 2011 to deliver life skills through the curriculum. In total, 1 920 693 sets of Learning and Teaching Support Material (LTSM) were distributed to 24 628 schools. Life Skills Teacher Guides and Learner Activity books were reviewed for compliance with the National Curriculum Statement. LTSM distributed to schools included a range of materials on sexuality education, drugs and substance use, stigma, discrimination, peer pressure and HIV and AIDS. Functional peer education programmes have been established in 16505 primary and secondary schools<sup>7</sup> Local government is also playing a key role in public education and awareness as illustrated in the Mossel Bay case study.

<sup>5</sup> Ibid.

<sup>6</sup> WHO 2012 Statistics and UNGASS progress country Reports 2012.

<sup>7</sup> Global AIDS response progress report 2012.



## Mossel Bay Municipality



Alma Kritzinger.  
Photo: Trevor Davies

The project, presented at the SADC Protocol@Work summit by Alma Kritzinger, Gender and Disability Officer, aims to increase the community's level of awareness about HIV and its engagement with HIV services through door to door campaigning in relation to Article 27 of the SADC Gender Protocol. The project attempts to address the community's limited understanding of HIV prevention and particularly women's inability to negotiate for condom use and other services. Project staff conducted a community needs assessment prior to beginning community sensitisation. The objectives of the project are to:

- Develop mechanisms for enhanced coordination in advocating for Persons Living with HIV (PLHIV) to have access to treatment and human rights;

- Increase awareness in the community through door to door sensitisation; and
- Lobby for the design of effective programmes with other stakeholders.
- Coordinators determined that the residents of informal settlements in five neighbourhoods will be the project's target beneficiaries. The project also targets HIV-positive people and vulnerable children.

The successful project saw 56% of the target group reached through the door to door campaigning access HIV, water and sanitation services. One of the key lessons is that community engagement through door to door campaigns is cost effective and efficient in delivering face to face information. It can also contribute to behaviour change and increased use of vital services.

## Medical male circumcision

Medical Male Circumcision has been proved, through three Randomised Control Trials, to prevent heterosexual transmission to men by about 60%. The South African male circumcision programme has surpassed one million male circumcisions performed, preventing an estimated 200, 000 new HIV infections by 2025 and saving the country hundreds of millions of rand.

The programme's national technical support partner, the Centre for HIV/AIDS Prevention Studies (CHAPS), reports that new service delivery sites offering Voluntary Medical Male Circumcision (VMMC) have been opened in all nine provinces and more than 2,500 medical professionals have been trained to provide VMMC services. The program has been implemented following the model for optimising volume and efficiency of VMMC services. This innovative operations model, originating from South Africa, focuses on eliminating operational bottlenecks and allowing facilities do performs over 100 circumcisions per day during peak seasons and VMMC campaigns.

Under current national guidelines and policies, only trained Medical Doctors can perform the surgical procedure. This limits the number of men that can be reached through this intervention. The country will soon be embarking on introducing the PrePex device, which is a simpler procedure to perform, and can be performed by lower cadres of workers, therefore increasing the reach of the program.

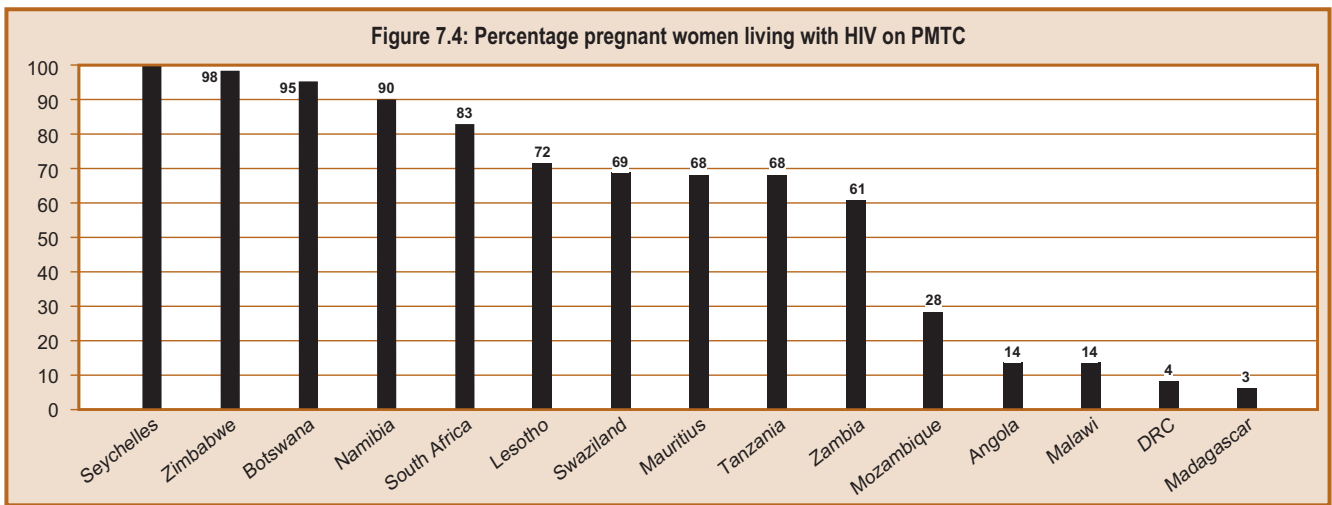
The success of this National program can be attributed to the strong leadership of the National Department of Health, under the stewardship of Minister of Health; financial support through PEPFAR and the Global Fund; and dedication from various NGOs in South Africa providing technical assistance and support to the department.<sup>8</sup>

## PMTCT

The Prevention of Mother to Child Transmission (PMTCT) programme in South Africa involves a series of interventions at various stages of pregnancy and during and after birth. The proportion of infants born to HIV-positive mothers who test HIV-positive within 2 months of birth is an important indicator of the success of comprehensive PMTCT programmes, as effective PMTCT programmes will reduce the proportion of babies who become HIV-infected. Data from the National Health Laboratory Service (NHLS) show a 15% increase from 2010 (39.2%) to 2011 (54.4%) in the percentage of infants testing for HIV within 2 months of birth<sup>9</sup>.

The government has scaled up coverage of PMTCT and the country now ranks in the top three for the region. In 2010 South Africa released new PMTCT guidelines, which are more in line with World Health Organisation (WHO) recommendations. In the guidelines HIV-positive pregnant women are advised to start treatment when their CD4 count drops below 350 cells/mm<sup>3</sup>; all pregnant women who test HIV-positive will begin receiving treatment at 14 weeks rather than in the last term of pregnancy; and HIV-positive women are advised to receive antiretroviral drugs postpartum.

<sup>8</sup> From an article by Dr Ntlotleng Mabena (MBChB, Dip HIV Man, DTM, MPH) Centre for HIV/AIDS Prevention Studies (CHAPS).  
<sup>9</sup> Global AIDS response progress report 2012.

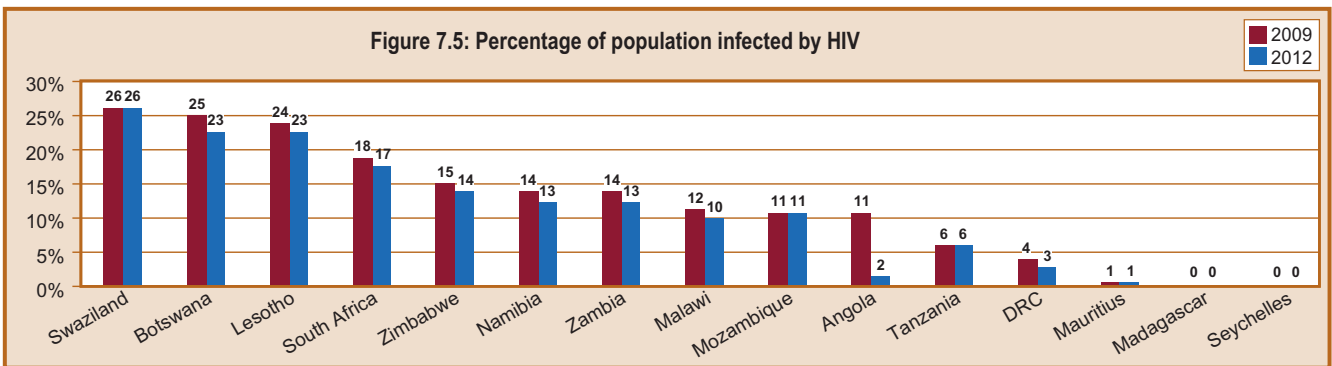


Source: Gender Links 2013.

Figure 7.4 shows PMTCT across countries in the region. In previous years South Africa compared rather poorly with only 50% of HIV pregnant women receiving this treatment. The situation has been turned around and the country now ranks third at 83%, behind the Seychelles and Botswana. It should also be noted that the two countries in first and second position have significantly smaller populations than South Africa, making the South African response all the more impressive.

### Bucking the trend

Encouragingly, concerted prevention efforts have resulted in steep declines in new infections in the world, with sub-Saharan Africa leading the way. Between 2001 and 2011 in Malawi, the rate of new HIV infections dropped by 73%, in Botswana by 71%, in Namibia by 68%, in Zambia by 58%, in Zimbabwe by 50% and in South Africa by 41%. In Swaziland, which has the highest HIV prevalence in the world, new HIV infections have dropped by 37%. This picture is heartening as countries continue to make huge strides toward reaching the UNAIDS 2015 target of zero new infections.



Source: UNAIDS 2010 and UNAIDS 2012.

Figure 7.5 illustrates that HIV prevalence rates continue to drop throughout the SADC region. Those countries with the highest prevalence in the region, South Africa, Zambia and Zimbabwe have managed to reduce these rates, as have countries like Angola and DRC, which have historically not had high HIV rates compared to

the other countries in the region. Zimbabwe showed significant reductions between 2001 (26.5%) and 2012 (14%).<sup>10</sup> Studies have linked this decline with

*"[New infection statistics] have emboldened our conviction that achieving an AIDS-free generation is not only possible, but imminent."*  
Michel Sidibé, UNAIDS Executive Director, 2012.

<sup>10</sup> Government of Zimbabwe. 2010. Factsheet HIV Decline in Zimbabwe - Positive Behaviour Change Makes a Difference. Harare: Ministry of Health and Child Welfare. [http://docs.google.com/viewer?a=v&q=cache:Q1kwMAwYdEJ:countryoffice.unfpa.org/zimbabwe/drive/FACTSheetHIVDeclineinZimbabweFinal.pdf+southern+africa+%2B+decline+%2B+hiv+prevalence+2010&hl=en&gl=za&pid=bl&srcid=ADGEE5JE8XNSU8w899NkfnqWqp6JWGin5\\_xxsHOy3oCWdzw9OOJdt5tn7uFL2o9LhmyQOzN7ZcKq3d3tMaXOA88MVsdt9O0y6lwcB6KINVO\\_0Uo18sr2habqjuL5uHcAtLDHJP4s&sig=AHIEtbS50g4CMx7kFiau kb7X2lVEiABIKQ](http://docs.google.com/viewer?a=v&q=cache:Q1kwMAwYdEJ:countryoffice.unfpa.org/zimbabwe/drive/FACTSheetHIVDeclineinZimbabweFinal.pdf+southern+africa+%2B+decline+%2B+hiv+prevalence+2010&hl=en&gl=za&pid=bl&srcid=ADGEE5JE8XNSU8w899NkfnqWqp6JWGin5_xxsHOy3oCWdzw9OOJdt5tn7uFL2o9LhmyQOzN7ZcKq3d3tMaXOA88MVsdt9O0y6lwcB6KINVO_0Uo18sr2habqjuL5uHcAtLDHJP4s&sig=AHIEtbS50g4CMx7kFiau kb7X2lVEiABIKQ)

population-level changes in sexual behaviour, particularly reductions in the number of sexual partners and increased uptake and use of condoms. South Africa, with the region's highest overall number of people infected, has stepped up efforts and programmes, including a large ART programme to address the epidemic.<sup>11</sup>

## Treatment



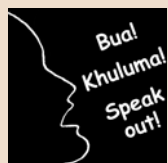
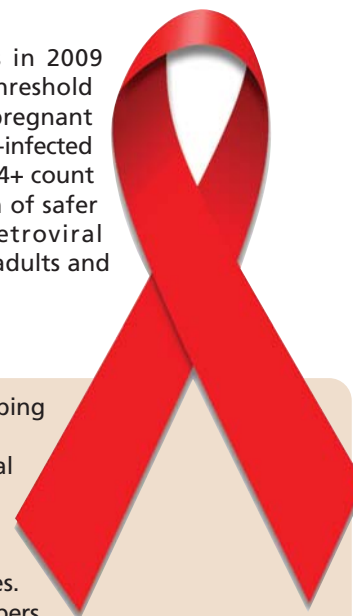
*The Protocol calls on state parties to ensure universal access to HIV and AIDS treatment for infected women, men, boys and girls.*

*"The more we lack the courage and the will to act, the more we condemn to death our brothers and sisters, our children and our grandchildren. When the history of our times is written, will we be remembered as the generation that turned our backs in a moment of a global crisis or will it be recorded that we did the right thing?"*

- Nelson Mandela, at 46664 Arctic, in Tromso, Norway (11 June 2004)

Despite the high prevalence rates the government of South Africa has to date reported one of the highest antiretroviral coverage in the region. In 2012 the antiretroviral therapy (ART) rollout programme recorded 1.8 million people ever started on ART since the commencement of the treatment programme. According to the country's 2012 UNAIDS report treatment initiation rates have reached 30,000 per month on average. This can be attributed to the revision of the

treatment guidelines in 2009 which increased the threshold for ART treatment in pregnant women and patients co-infected with TB and HIV to CD4+ count 350, and the provision of safer and effective antiretroviral therapy regimens for adults and children.



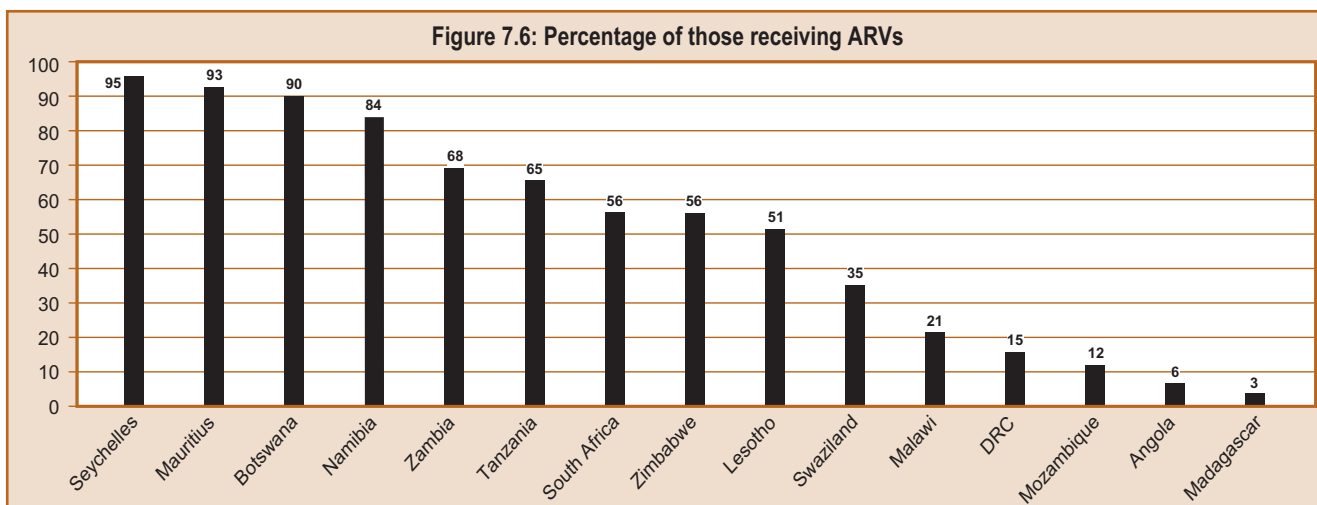
- Ensure universal access to ARV's for women. This will also help in curbing mother to child transmission.
- Mobile clinics can be used to lack of access of health services in rural areas.
- Establish support groups for people living with HIV.
- Department of Health to address the problem of shortage of resources

and equipment. For instance, care givers are sometimes forced to work without gloves.

- Address stigma and discrimination against people infected with the virus. Family members must be included in such interventions.
- Train and work in close collaboration with traditional healers.
- Women often take care of themselves and they are very active in checking their status. Men, on the other hand, are often reluctant to test. When they test positive, some of them fail to take the medication as prescribed. As a result, default and resistance to drugs is higher amongst men.
- In some cases men do test and when they find out that they are positive, they either disappear or take treatment in secret without informing their partners.
- Involvement of male nurses in the treatment and support of men living with HIV.
- Community education involving men should target churches, workplace, taverns and sheebens, and many other places where men gather.
- In certain cases, women also keep their status private because of fear of abuse.
- Sometimes the attitude of the nurses borders on being emotionally abusive to the patient. For example, it is not uncommon for people who are positive to be shouted at in the presence of others.

<sup>11</sup> UNAIDS Country Progress Report, 2010.

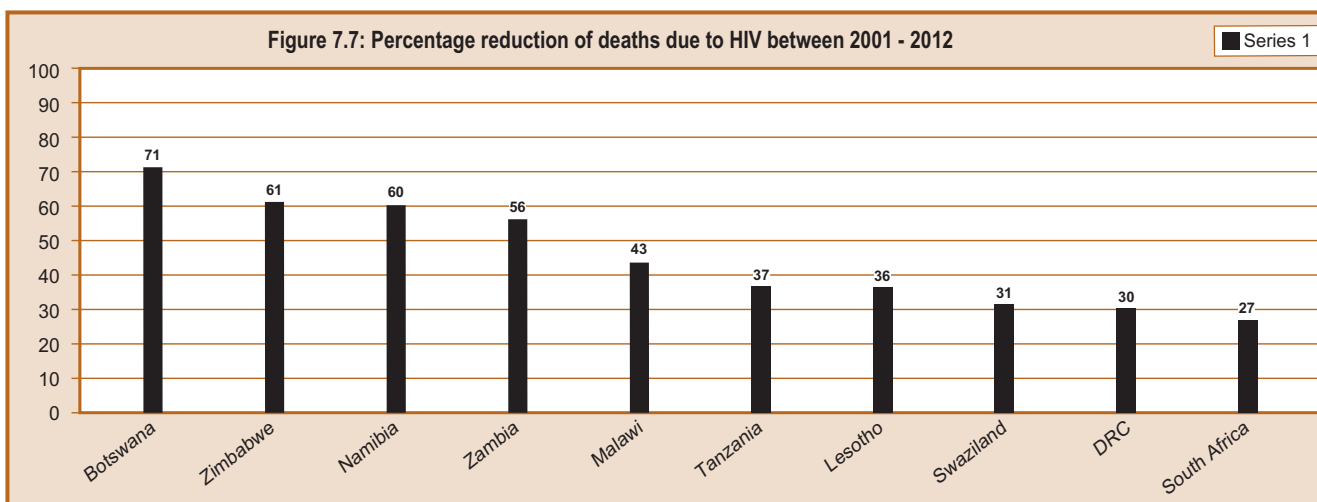




Source: UNAIDS 2012.

South Africa has rapidly scaled up its ART programme, which is the largest in the world. Close to two million South Africans have accessed treatment to date, compared to one million in 2009. Figure 7.6 shows,

however that this is still only 56% of those living with HIV and AIDS. The target is to ensure that three million people are on treatment by 2015.



Source: UNAIDS 2013 World Aids Day Result Report.

The rapid expansion of treatment has resulted in a marked reduction in the number of deaths in the region. The UNAIDS 2013 Results report notes that sub-Saharan Africa has cut the number of deaths from AIDS-related causes by 32% between 2005 and 2011, with the largest drop in AIDS-related deaths recorded in some of those countries where HIV has the strongest grip. For example, Figure 7.7 illustrates that South Africa reduced the number of deaths in this time period by 27%, which amounts to approximately 100 000 deaths.<sup>12</sup> Botswana, meanwhile, saw the largest per capita reduction at 71%.

The rapid expansion of access to ART in South Africa, the largest HIV treatment programme in the world, is not without its challenges. Some of these include multiple monitoring systems that vary from province to province. The National Department of Health has developed a new three-tiered patient-based monitoring system for ART, which is being implemented throughout the country in phases. This will enable certain health facilities with larger numbers of ART patients the use of an electronic monitoring system.<sup>13</sup>

<sup>12</sup> UNAIDS 2012 World AIDS Day Report: Results.

<sup>13</sup> Global AIDS response progress report 2012.

However, many problems still hamper access to ARVs, most of which are centered on infrastructural capacity and skills shortages of health personnel. South Africa has to date trained over 10,000 professional nurses specifically for the ART roll out under a programme called Nurse Initiated Management of ART (NIMART).

The government is committed to providing an appropriate package of services that includes wellness, opportunistic infections management, ART, and nutrition to children and adolescents who are HIV positive and/or exposed. In 2009, 86,270 children were receiving treatment. According to the latest WHO guidelines, this means that 54% of children in need of HIV treatment in South Africa are receiving it (WHO/UNAIDS/UNICEF 2010).

## Care work



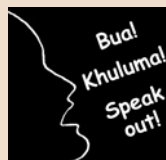
*Article 27 of the Southern Africa Development Community (SADC) Protocol on Gender and Development calls on State Parties to develop and implement policies and programmes to ensure appropriate recognition of the work carried out by care-givers, the majority of whom are women, allocation of resources and psychological support for care-givers as well as promote the involvement of men in the care and support of People Living with HIV and AIDS.*

During the months of May and June 2009, the Gender and Media Southern Africa Network (GEMSA) conducted a policy audit of care work in South Africa. Interviews were held with HBC workers, HIV/AIDS organisations and International NGOs. GEMSA aimed to evaluate current and future provisions for care-givers in the country, to identify policy gaps, and to provide recommendations on how stakeholders can strengthen the care work programme. Ultimately, the findings from this report will contribute to a model home-based care policy for the Southern African Development Community (SADC) region.

To accurately reflect on conditions in the country, GEMSA held a focus group meeting in Johannesburg and a series of interviews. Researchers identified participants through desktop research and discussions with organisations involved in care work. The meeting brought together 12 community home-based care organisations. GEMSA conducted separate meetings and interviews with two of the largest home-based care groups in Johannesburg, Orange Farm and another affiliated organisation.

GEMSA discovered that home-based care organisations are not fully aware of the processes that are currently taking place within the Department of Social Development (DSD) and the Department of Health (DOH) in South Africa that regulate care work in the country. Thus, lack of access to information such organisations by government has led most of the organisations to source funds from donors and these funds are allocated conditionally to what the donors stipulate. Another emerging issue has been the delay in funding projects and incidents of corruption within the government departments.

Some home-based care organisations confirmed that funds were being taken back after being released late, during the past the financial year, with the departments demanding that funds be returned due to lack of use. There are great challenges with delayed funds from government with the result that organisations are unable to spend the funds allocated on time and consequently need to return the funds, despite the situation of financial duress they find themselves in. Consequently, home based care organisations are on the verge of closing due to lack of funds.



- Community Health Workers must be trained, upgraded and accredited. Currently, they work as volunteers for a long time. If they do not have Matric certificate, they end up not achieving anything.
- Improve training and support for unpaid community based care givers who are mostly women. Unemployed men must also be encouraged to participate in the initiative. Society look down upon male caregivers; arguing that it is a woman's job. Male nurses can also be encouraged to run programmes for men in communities.
- Some orphans and vulnerable children end up not being help to get anywhere because of not having necessary qualifications and ID books. Government must extend and support care centres within communities.
- One of the pressing needs is poverty and malnutrition. Government must provide support groups with food and skills to be able to help themselves e.g. community vegetable gardens, arts and crafts, cooking skills etc.
- Parenting support groups are a priority. Raising children in contemporary society is a challenge for many mothers.

## Making care work count - demanding responsive governance

Rose Thamae, director and founder of *Let us Grow*, a community-based organisation in Orange Farm in Johannesburg shared how the Making Care Work Count campaign advocating for care work policies and recognition of care work has made a difference to her work.

Thamae, living positively with HIV and AIDS is fondly known as "Mum Rose" in her community a testimony of the leading role she has played in providing care and treatment for people with HIV and AIDS.

Mum Rose founded *Let Us Grow* in 1996 after a life changing experience. "Let us Grow project was initiated after I was gang raped and diagnosed with HIV. I learnt how to live positively through the care and support I received from a care group. This made me realise that there is great need for other people to have the same information that I had."

The South African government does not fully support all their needs despite the fact that two ministries who oversee care work in the country Department of Health (DOH) and Department Social Development (DSD) have a Home and Community Based Care and Support Programme. What exacerbates the problem is that most home based care organisations are not fully aware of the care work policy processes that are taking place at the DSD and the DOH and sometimes to do not access funding and resources available to them.

While the home based care services programme recognises and supports care workers by providing training that is accredited and stipends, the approaches to training by DOH and DSD are different. DSD has adult training given to care givers who did not matriculate and DOH insists that caregivers must have matriculation certificates. Thamae is concerned that many important issues have been overlooked, as some care workers are not given an opportunity to undergo training.

On the positive side care workers get 65 days care training provided by the DOH, they undergo HIV and AIDS training and psychosocial support. "I was one of those people who are strong advocates that care work must count. I will not rest until I see that the valuable work we do is fully recognised by government. Government should now adopt the care work policy framework that has been in draft form for almost three years now."

She has many other concerns.

"To keep the organisation going we need funding that will support our projects, the Department of Health has been funding our projects but not all our expenses are covered. They pay caregivers but this has not been enough. Out of the 50 caregivers, only 15 receive a

monthly stipend of R1200. We could have managed to pay all caregivers if some of the donors who used to support us had continued to fund us, but after they pulled out we experienced serious financial constraints and this prompted us to cut down the budget.

Since we cannot afford to provide all the required resources we sometimes receive donations such as clothes, school uniforms for the orphans and vulnerable children that we take care of. Sparo Hospice provides us with food, but we do not have these donations frequently, we have to wait until they call us even if we are desperate for food we have to wait.

For us to run our organisation we need to motivate the care workers, these care workers have families at home and they need to provide food for their children, yet they keep on working on voluntary basis. Most of them are females hence forcing them to have multiple roles to have extra income".

"Men don't want to work as volunteers or for stipends or even dry season as they are called they want salaries and they know the worth of our jobs, so how are we going to make them get involved in care work," comments Bonginkosi Zwane a care giver working at *Let Us Grow*.

Mum Rose insists: "We need to be recognised. We need to be supported unconditionally because we fail to run certain important projects because we do not have money. For instance, the orphan and vulnerable children programme has been hanging for a long time now. It is still waiting to be funded. I have managed to bring the community together and work towards achieving one goal, but with all these challenges we feel we are failing to reach some of the targets we set ourselves.

"Despite undergoing care work training, we are not considered as professionals. In fact the draft policy does not cover those who are not registered with professional bodies. The relationship is very bad, we are divided yet we do the same job as primary care givers.

"Dedicated men and women providing care work also get affected when our programmes are not going on as planned, I have had others who have left us and joined other organisations and this hinders our progress, because our aim is to have many care providers.



Mum Rose leading *Let Us Grow* in advocacy for remuneration for care workers among several demands, December 2011. Photo: Gladys Muzirwa



“We need logistical support. For example, there are certain times when we run out of condoms and ARVs yet we still have to encourage the patients to take their medication. Others lose hope to live and we feel as though we are not doing enough as an organisation, but thank God that we still continue to work.”

“Sometimes our work is fatal; it makes us ill,” Hilda Moloji, one of the care givers. “We contract Tuberculosis and bring it to our families because we do not get support from government but because we love what we do, we work anyway,” she reflected.

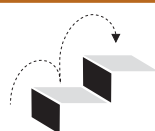
Services undertaken by care providers may be classified in three categories: prevention, treatment and support. Table 7.2 details the types of activities included in each area.

**Table 7.2: National Plan on Carework**

Issue	Policies	Opportunities	Recommendations
Remuneration	This is not stipulated in any policy document.	SANAC, DSD and DOH need to work out the process more clearly to avoid role confusion.	<ul style="list-style-type: none"> <li>Mobilise resources for sustainable compensation.</li> <li>Strategise on how stakeholders can collectively pay care-givers.</li> <li>Explore the potential for government subsidies for HCBS organisations to have salaries paid out of the funds that DSD provides.</li> </ul>
Logistic and material support	DSD gives out food supplements and parcels (although this is ad hoc and not well regulated).	This would assist organisations that are in need of supplies and rely on donations from donors, etc. There is need to give out more materials such as HCBS kits.	<ul style="list-style-type: none"> <li>Raise awareness for HCBS to collect materials and alleviate the delays that occur when donors run out of materials.</li> <li>Strategise on stakeholder cooperation in this area and examine potential for government subsidies for HCBS groups.</li> <li>Create a body that links Home Based Care Organizations to Home Based Care Services and informs of materials and supplies available constantly.</li> </ul>
Training/professional recognition	DSD and DOH need to make this criteria clear as it currently seems grey; information is required.	There is a need to train care workers as the area of care work changes rapidly. Recognition of training would also create opportunities for care-givers to work in other areas of need such as hospitals.	<ul style="list-style-type: none"> <li>Determine strategic minimum education requirements to maximise the number of older care-givers eligible for training.</li> <li>Provide greater clarity on what will happen to care-givers who do not qualify for training.</li> <li>Plan the logistics and resources required to re-train all community home-based care-givers.</li> </ul>
Psychosocial support	There is a document within the policy framework of the DSD; although it is unclear to what extent this has been implemented.	If implemented, this policy will help to ensure the physical and mental wellbeing of the care-giver.	<ul style="list-style-type: none"> <li>Identify, secure and train and accredit appropriate number of HCBS supervisors in diverse areas of management.</li> <li>Explore possible opportunities for collaboration between the care-givers and local level social workers.</li> <li>Develop support networks based on information on where and how HCBS organisations are operating.</li> <li>Publicise and utilise the DSD and DOH home-based care forums for sharing challenges and successes.</li> </ul>
Gender equality	This is noted within the policy framework documents for HCBS.	Policies need to articulate clearly that there is need to have men in the arena of care work. This would lessen the burden of care for women and sharing of responsibilities with men.	<ul style="list-style-type: none"> <li>The policy and guidelines for implementation should stipulate active recruitment and engagement of men on HCBS-this could be a requirement for organisations seeking funds through DSD and DOH.</li> <li>HCBS organisations should reach out to men's forums, traditionalists, the church and other respected community authorities to discuss the important role of men in care work.</li> </ul>

Source: GEMSA South Africa care work report 2012.

As rapid increases in availability of treatment becomes a reality across the region, it is necessary to pause and consider the role of community and home-based caregivers in the future. Some areas in which caregivers will continue to be needed are: ongoing engagement in the HIV continuum of care, including provision of psychosocial support; awareness raising for all forms of prevention, including PMTCT; treatment readiness and continuing support for treatment adherence; as well as community mobilisation to decrease stigma.



## Next steps

- More strategies need to be implemented to reduce the rate of infection in the country
- The national strategic plan needs to be updated for post 2015.
- The access to medication is still a challenge with health professionals selling the medication to patients and the increase in the number of drug addicts that use the drug to treat feed their habits.
- The campaign for remuneration of care givers needs to intensify, and be adapted in light of the uptake on treatment and care.