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**CHANGES IN POLICY AND PRACTICE IN THE HIV ARENA  
IN SOUTH AFRICA**

Erika van Vollenhoven\*

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\* Erika van Vollenhoven is an educational psychologist in private practice.

## I. INTRODUCTION

Southern Africa is the region worst-affected by the HIV and AIDS epidemic. Several factors are contributing to this human tragedy, including: poverty and social instability, high levels of sexually transmitted infections caused by unsafe sex, marginalized status of women; sexual violence, high mobility (particularly migrant labour), overcrowded prisons, rites of marriage, rites of death and lack of political leadership.<sup>1 2</sup>

South Africa has the fifth highest prevalence of HIV in the world. It is estimated that almost 21.5% of its population is infected. The UNAIDS Global Report<sup>3</sup>, estimated the number of AIDS related deaths in South Africa in 2003 ranged anywhere between 270 000 and 520 000. 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.<sup>4</sup>

The number of new infections is still rising with no signs of reaching a natural limit. According to the South African National Department of Health's latest National HIV and Syphilis Antenatal Sero-Prevalence Survey, an annual survey that uses a statistical model to estimate the prevalence of HIV in the population based on the prevalence among women tested at state antenatal clinics, released in September 2004, roughly 5.6 million South Africans were living with HIV in 2003.<sup>5</sup> Efforts to curb new infections have only had limited success, as behaviour change and social change are long-term processes. Indeed, factors that predispose people to infection – such as poverty, illiteracy, and gender inequalities – cannot be addressed in the short term. The impact, of the HIV and AIDS epidemic is proving to be at its worst at community and household level. The hardship for those infected and their families begins long before they die. They suffer from social stigma related to suspected infection, panic that often follows diagnosis, loss of income and support when a breadwinner or caregiver becomes ill, diversion of scarce household resources to provide care, emotional stress on family members, particularly the girl child caring for terminally ill parents, and trauma of bereavement and orphanhood. .

Women face a greater risk of HIV infection. In South Africa the differential in infection rates between women and men is most pronounced for the age group 15 – 24 years with the infection ratio of 20 women to 10 men. Young women tend to have partners who are much older than themselves, who have other girlfriends and are more likely to be HIV infected.

The ASSA 2002 model<sup>6</sup>, a model developed under the auspices of the AIDS Committee of the Actuarial Society of South Africa, calculates that 311,000 people died because of AIDS in 2004 - comprising 44% of all deaths that year. Among adults age 15-49 years, it estimates that 70% of all deaths were due to AIDS.

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<sup>1</sup> <http://www.avert.org>

<sup>2</sup> *Olive Shisana (Principal Investigator); Leickness Simbayi (Project Director). 2002 .Nelson Mandela HSRC Study of HIV/AIDS: Full Report\_South African national HIV prevalence, behavioural risks and mass media. Household Survey 2002.HSRC: Pretoria*

<sup>3</sup> <http://www.unaids.org>

<sup>4</sup> <http://www.avert.org>

<sup>5</sup> National Department of Health. 2004. National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2004. National Department of Health: Pretoria.

<sup>6</sup><http://www.commerce.uct.ac.za/care>

## II. THE GOVERNMENT'S RESPONSE TO HIV AND AIDS<sup>7</sup>

The beginnings of a coordinated public policy response to HIV and AIDS date back to 1992, with the formation of the National AIDS Coordinating Committee of South Africa (NACOSA). Progress in implementing the NACOSA plan was assessed in 1997 by the South African National STI and HIV and AIDS Review.

In 2002, Building on this review, and on an extensive consultation process, government launched its five-year Strategic Plan for HIV and AIDS. This plan provided the general framework of policy interventions geared towards initiating and executing a comprehensive national response to the epidemic. The strategic plan identified four key areas of intervention, namely:

- prevention;
- treatment, care, and support;
- research, monitoring and surveillance; and
- legal and human rights.

In April 2002, after reviewing its approach to HIV and AIDS, Cabinet reaffirmed its commitment to the Strategic Plan. Noting progress in the overall implementation and significant impacts beginning to take place, Cabinet decided on a number of measures to strengthen and reinforce these efforts, including:

- Strengthening partnerships, especially via the South African National AIDS Council (SANAC).
- Continued use of nevirapine in preventing mother-to-child HIV transmission, and development of a universal rollout plan.
- Providing a protocol for a comprehensive package of care for survivors of sexual assault, including post-exposure prophylaxis with antiretroviral drugs.
- Ensuring that no one should be turned away without appropriate treatment and management of any infection or illness, irrespective of HIV status.
- Noting that antiretroviral treatment can help to improve the conditions and health of people living with AIDS if administered at certain stages in the progression of HIV and in accordance with international standards,
- Commitment to continue its efforts to remove systemic constraints on access to these drugs.
- Poverty alleviation and nutritional intervention, to encourage investigation into alternative treatments, particularly supplements and medication for boosting the immune system.

In July 2002 government established a Joint Health and Treasury Task Team (JHTTT) to investigate issues relating to the financing of an enhanced response to HIV and AIDS, based on the Strategic Plan. A particular focus of the Task Team was on the second component of the Strategic Plan, namely treatment, care and support for those infected and affected by HIV and AIDS.

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<sup>7</sup> National Department of Health. 2003. Operational Plan for Comprehensive HIV and Aids Care, Management and Treatment for South Africa. Department of Health: Pretoria

At the August 2003 meeting, Cabinet received the Report prepared by the JHTTT that was charged with examining treatment options to supplement comprehensive care for HIV and AIDS in the public health sector. This report provided recommendations that included scaling up of current policy interventions and integrating additional interventions, including the option of antiretroviral therapy available for people with AIDS.

Following that discussion in August 2003, Cabinet instructed the Department of Health to develop a detailed operational plan on an antiretroviral treatment programme by the end of September 2003. In view of that task, the Minister of Health appointed a National Task Team to assist in the development of a detailed operational plan with the following terms of reference:

- Development of provincial implementation plans, including a resource and training centre in each province, to help ensure the delivery of high quality treatment and care; a schedule for rollout across district hospitals and health centres and a forecast of staffing requirements. Provincial operational plans are to be based on the district health systems within each province.
- Procurement and/or production of necessary medications and consumer goods at the lowest prices possible, and an increase in the capacity and security of the drug distribution system.
- Upgrading of the national health laboratory system to handle a significant increase in diagnostic testing and monitoring of patient safety.
- Extending an integrated nutritional programme for people living with HIV and AIDS.
- Development of a research agenda to support the programme, including engagement of South African academic centres and research institutions.
- Establishment of a robust system to monitor efficacy of the intervention, adverse drug events, resistance, improvement and coordination of patient information systems.
- Development of staffing norms and standards for the delivery of antiretroviral therapy and assessment of human resource needs, including health system managers, clinicians, nurses, pharmacists, nutritionists and counsellors.
- Creation of a Programme Management Unit to coordinate the implementation of the programme and recommendations for its functions, structure, staffing and cost.
- Development of a communications plan for health providers and the public, including what to expect from the proposed treatment programme.
- Development of a detailed five-year programme budget and an estimated ten-year budget for the treatment programme.
- Development of a detailed implementation schedule.

The Plan is premised on the following principles:

- Ensuring that the great majority of South Africans who are currently not infected with HIV remain uninfected. Messages of prevention and of changing lifestyles are therefore pivotal in managing the spread of HIV and the impact of AIDS. Important in supporting these efforts in the broader context are the social programmes by the government and civil society that aim at poverty reduction through improved access to information, nutrition, job creation and social support, and strive to improve education and to bring about moral renewal.

- Enhancing efforts in the prophylaxis and treatment of opportunistic infections, improved nutrition and lifestyle choices.
- Effective management of those HIV-infected individuals who have developed AIDS-defining illnesses, through appropriate treatment of AIDS-related conditions (including the possibility of using antiretroviral therapy in patients presenting with low CD4 counts to improve functional health status and to prolong life), and suitable palliative and terminal care where treatment has run its course.

The Task Team held numerous discussions with representatives of all nine provinces, including several meetings with the provincial Health MECs. It also met with a wide range of stakeholders, including non-governmental organizations, professional associations, trade associations, labour organizations, research institutions, and HIV and AIDS clinicians. These meetings included visits to a wide variety of settings, urban and rural, resourced and under-resourced. Experts from the William J. Clinton Presidential Foundation assisted the Task Team, and will continue to provide operational support in the initial years as required.

The roll-out of the ARV programme is proving to be a slow process for the following reasons. First, the Department of Health needs to address major capacity and infrastructure constraints. Second, the agency continues to send confusing messages about the role of nutrition and traditional medicine, and safety and efficacy of registered drugs that have been provided in the private sector (and at taxpayers' expense to MPs) for many years. By the early 2005 only approximately 30 000 patients were receiving ARV therapy through the state programme. The Operational Plan commits the government to providing ARV treatment to 1,650,000 people who need it by March 2008.

The amount of R350-million budgeted for spending by the Departments of Health, Social Development and Education for the FY 2001/2 has been increased to R1-billion the FY 2003/4 and will be increased to R1.8-billion for 2005.

Health care workers have been overwhelmed by the impact of HIV and AIDS on the public health service, with the bulk of resources in many facilities allocated to treat people with opportunistic infections or dying from AIDS-related illnesses. This has resulted in overcrowding of already under-resourced hospitals, resulting in patients not being able to receive adequate care from health professionals working in very difficult and stressful conditions. Staff morale is often very low, due both to poor conditions but also to the emotional distress of being unable to treat people effectively. Furthermore, many health workers are themselves living with HIV and AIDS. Often medical staff find themselves on the frontlines of the AIDS epidemic and bear the brunt of complaints about the health system. Working conditions are made worse by lack of specialized training and persistent staff shortages.

While many health workers have responded to this crisis by leaving the country to work in better-resourced clinics and hospitals overseas, many others have joined the advocacy movement for access to treatment as part of a wider campaign to build the public health service.

In February 2004<sup>8</sup>, the South African government admitted that delays in the procurement process and lack of training for doctors were still delaying the urgent rollout of ARV treatment.

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<sup>8</sup> [www.aidsmap.com/news/newsdisplay2.asp?newsId=2565](http://www.aidsmap.com/news/newsdisplay2.asp?newsId=2565)

The policy states that the government wants to provide comprehensive viral-load testing for HIV positive people, something for which national medical infrastructure is not equipped. The government hasn't stated yet whether they will allow the lack of viral-load testing facilities hold up the provision of ARV medication. The overall implementation is going to be very demanding, given that the health-care system is short on trained staff in some locales, due to the effects of HIV.<sup>9</sup>

At the beginning of 2000 Thabo Mbeki sent a letter to world leaders expressing his doubt that HIV was the exclusive cause of AIDS and arguing for a full consideration of its socioeconomic causes. He subsequently invited scientists who shared his view to sit with the “orthodox” experts on AIDS on a presidential panel to advise him on appropriate responses to the epidemic in South Africa. Until April 2002, when Mbeki formally distanced himself from the AIDS "dissidents," the international scientific community's interest in South African policies on AIDS was almost exclusively focused on the polemic raised by the president. His statements questioning the accuracy of AIDS statistics and his views on poverty as a cause of immune deficiency and on the dangers of antiretrovirals, together with government stalling on the roll out of nevirapine to prevent transmission of HIV from pregnant mothers to their babies, dominated the debate.<sup>10 11</sup>

However, the July 2002 Constitutional Court judgment ordering the government to make nevirapine universally available to pregnant women infected with HIV, was followed in October by the cabinet statement supporting wider access to antiretrovirals, may have finally ushered in a new era in the national response to the epidemic.<sup>12</sup>

The experiences of other resource-poor countries indicate that the time-period between HIV diagnosis and death, in an impoverished area, can be as little as two years. Given this estimate treatment must be implemented immediately or an estimated two million of South Africa's population could be dead within the next year.<sup>13</sup>

### **III. HIV/AIDS AND LABOUR IN SOUTH AFRICA**

The three biggest Trade Unions in South Africa are the Congress of SA Trade Unions (COSATU), the National Council of Trade Unions and the Federation of Unions of South Africa. These federations have collaborated closely on the programme that aims to enhance the capacity of trade unions to carry out HIV and AIDS prevention. In January 1999 the Department of Health facilitated formation of a "Trade Union Task Team". The task team has trained and expanded a cadre of trade union leaders with more detailed knowledge of HIV and AIDS.

South African labour unions, through the Congress of SA Trade Unions (COSATU) have also long supported the demand for adequate care and treatment for people living with HIV and AIDS. Workers who are affected by HIV and AIDS are part of a diverse group consisting of

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<sup>9</sup> <http://www.avert.org>

<sup>10</sup> Sidley, P.2000. *Clouding the AIDS issue* .British Medical Journal: 320:1016

<sup>11</sup> Makgoba, M.2000. *The peril of pseudoscience*. Science 288:1171

<sup>12</sup> Fassin, D. 2003. *AIDS in South Africa: beyond the controversies*. British Medical Journal:326:495-497

<sup>13</sup> <http://www.avert.org>

primary breadwinners who risk losing their income if they become sick, partners of people with HIV and AIDS, caregivers to sick people, and guardians to orphaned children, among others. In the early days of the epidemic, labour unions had to confront open discrimination by employers, such as compulsory HIV testing, and retrenchment of workers who are HIV positive or who are already infected. Mineworkers were among the first group of workers recognized to be vulnerable to HIV infection, due to high levels of mobility and tendency to have more than one sexual partner, often including prostitutes. However, recently infection rates among other workers, such as educators and health professionals have risen alarmingly. Unions are seeking both individually and collectively workplace testing, counselling and treatment programmes, and have fought for the legal rights of infected and affected workers. They are also very concerned about the working conditions of health care workers.

COSATU is a partner in the ANC government but has opposed the ruling ANC over some aspects of its HIV and Aids policy. It has partnered the Treatment Action Campaign (TAC)<sup>14</sup> demanding fair access to treatment. It has also joined the Basic Income Grant Coalition in the campaign for a universal grant to ensure all South Africans can meet their basic needs. It also engages with business interests, pharmaceutical companies and individual donors to improve access to affordable treatment.

In 2002, COSATU produced a Draft Discussion Document advocating for a national treatment plan.<sup>15</sup>

Employer's organizations have strong networks and are well-designed to carry the message of HIV and AIDS prevention, care and support, and treatment across to their members. The most influential organizations are: the South African Chamber of Business (SACOB), Business South Africa (BSA) and the Afrikaans Handels Instituut (AHI).

The South African Business Coalition on HIV and AIDS (SABCOHA) was registered as a company in May 2001. It was recognized by the South African National Aids Council and the then Deputy President as the body representative of business stakeholders on HIV and AIDS policies.

#### **IV. HIV/AIDS AND NGOS IN SOUTH AFRICA**

Since 1998, when then Deputy President Thabo Mbeki launched the Partnership Against Aids, the government has adopted a broad-based, multi-sectoral approach towards fighting the disease. Given that HIV and AIDS affects every sector of society, all initiatives – awareness campaigns, care for the affected and research – are strengthened by a partnership approach.

A wide range of NGOs have responded to the HIV/AIDS crisis. They engage in awareness and advocacy campaigns, research, training, coalition building, education, welfare and health service provision, materials production, orphan care, counselling and other activities. It is NGOs that have driven the campaign for access to treatment, lower drug prices, improved care and more effective policy on HIV and AIDS.

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<sup>14</sup> <http://www.tac.org.za/>

<sup>15</sup> <http://www.aids.org.za>

Many AIDS awareness campaigns run by the government and NGO partners such as LoveLife and Soul City are now beginning to show tangible results. There is a high level of awareness among the youth on HIV/Aids – around 90% – but the pressing challenge is to ensure that this awareness translates into a sustained behavioral change.

Life skills education, which incorporates HIV/AIDS education, is now a compulsory part of the school curriculum and is to be fully implemented across the entire school system by the end of 2003<sup>16</sup>.

LoveLife<sup>17</sup> is a nationwide campaign that aims to promote healthy sexual behaviour among adolescents and to reduce the incidence of HIV/AIDS, sexually transmitted diseases and teenage pregnancies. LoveLife uses a widespread media campaign targeting adolescent audience, and offers educational, recreational and sexual health services in under-resourced areas.

Soul City<sup>18</sup> uses mass media to promote awareness around health issues. Soul City has won international awards for its success in integrating education and entertainment using popular radio and television drama.

NGOs' relationships with government have varied – on the one hand, the National Association of People Living With AIDS has received government funding, and, on the other, TAC has been attacked by the government for its protests and litigation efforts over the response to the epidemic.

Enormous financial resources have been channeled to NGOs by donors but it has often been difficult for smaller, lesser known organizations to attract donations. Moreover, some donors tend to push for particular outcomes, such as orphanages or high-profile prevention campaigns, instead of responding to local needs or priorities.

Services have tended to be fragmented but in recent years NGOs have come together in coalitions to promote a more coherent response. Directories of AIDS service organizations have been developed and information on funding for HIV/AIDS work has been collated.

Entities such as the Joint Civil Society Monitoring Forum have brought together NGOs, business, government, donors and health professionals to work together in the fight against the epidemic.

## **V. THE SOUTH AFRICAN AIDS VACCINE INITIATIVE (SAAVI)**

The South African AIDS Vaccine Initiative (SAAVI) was formed in 1999 as a lead programme of the Medical Research Council (MRC)<sup>19</sup> of South Africa. Primary funding was received from the Department of Health (DoH), the Department of Science and Technology (DST) and Eskom. In 2004 Transnet and Impala Platinum have also come on board as additional sponsors.

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<sup>16</sup> <http://education.pwv.gov.za/HIVaids>

<sup>17</sup> <http://www.lovelife.org.za/>

<sup>18</sup> <http://www.soulcity.org.za/>

<sup>19</sup> <http://www.mrc.ac.za/>

SAAVI was established to co-ordinate research, development and testing of HIV/AIDS vaccines in South Africa. SAAVI is based at the MRC and is working with key national and international partners to produce an affordable, effective and locally relevant HIV/AIDS vaccine in as short a time as possible.

SAAVI contributes to international scientific knowledge through its focus on the development of subtype C HIV/AIDS vaccines (HIV subtype C accounts for over 90% of infections in the southern African region). Most HIV vaccines that have been tested in clinical trials to date were developed for the subtype B virus. However, there is no conclusive scientific evidence, as yet, showing that a vaccine based on one subtype of HIV will or will not protect against infection with another HIV subtype. Multiple trials of candidate vaccines based on different clades are therefore needed.<sup>20</sup>

## **VI. HIV/AIDS AND THE LAW**

The way in which employees with HIV or AIDS are treated in the workplace has many legal implications. This wide range of vital societal implications reaches from the Constitution down to a shop floor agreement between employer and employee. Legislation and the way it is applied will however continue to evolve and meet the dynamic knowledge and understanding of the epidemic.<sup>21</sup>

The South African Constitution (Act 108 of 1996) is the highest law of the country and all other laws must comply with its provisions. The Bill of Rights within the constitution sets out a number of rights, which protects employees. Our labour laws are consistent with the Constitution.

There are seven key pieces of labour legislation in South Africa, including one that applies to the mining sector specifically. These include:

- the Employment Equity Act No. 55 of 1998 (EEA),
- the Labour Relations Act No. 66 of 1995 (LRA),
- the Promotion of Equality and Prevention of Unfair Discrimination Act No. 4 of 2000,
- the Basic Condition of Employment Act No. 75 of 1997 (BCEA),
- the Occupational Health and Safety Act No. 85 of 1993 (OHSA),
- the Compensation for Occupational Injuries and Disease Act No. 130 of 1993 (COIDA),
- the Mines Health and Safety Act No. 29 of 1996

HIV/AIDS is explicitly referred to only in the Employment Equity Act, but there are provisions in all the other Acts which have relevance to HIV and AIDS. The Employment Equity Act will become the most important point of reference for legal decisions concerning the management of HIV and AIDS in the workplace because it expressly protects employees against unfair discrimination on the basis of their “HIV status”

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<sup>20</sup> <http://www.safrica.info/>

<sup>21</sup> Whiteside, A and C Sunter. 200. AIDS: The Challenge for South Africa. Human & Rousseau Tafelberg: Western Cape

There are also other pieces of legislation, policies, protections and guidelines within the common law that have an impact on the management of HIV/AIDS in a workplace. The following examples are not necessarily directly employment related. These include:

- the Medical Schemes Act No. 131 of 1998,
- the Department of Health's Draft National Policy on Testing for HIV, and
- common-law protection of the right to privacy and dignity.

South Africa has become signatory to a number of international agreements and codes of conduct, such as the International Labour Organisation (ILO) Convention 111 on Discrimination (Employment and Occupation), 1958. The only one that specifically relates to HIV and AIDS in the workplace is the Southern African Development Community Code on AIDS and Employment, which was approved by the Council of Ministers in September 1997. This Code provides a non-discriminatory framework for managing HIV and AIDS in the workplace.

## **ABOUT THE AUTHOR**

**ERIKA VAN VOLLENHOVEN** is an educational psychologist in private practice, with a specialisation in Life Skills and Sexuality Education with a view to HIV/AIDS and substance abuse prevention strategies. She has been a leader in planning, designing and developing of Prevention, Care and Support programmes in the work place for those infected and affected with HIV and AIDS.