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**The Public Sector HIV/AIDS Treatment Roll-Out
Campaign in the Western Cape:**

**A Case Study Highlighting Success Factors and
Challenges**

Nadia C. Fuleihan: FLHNAD001

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Compulsory Declaration

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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Abstract

Until recently, the national implementation of a public sector Antiretroviral Therapy (ART) programme in South Africa seemed financially impossible. Drastically reduced prices for Antiretrovirals (ARVs) combined with substantial donor funding and the long-awaited adoption of a national treatment plan, have, however, shifted the debate. Now the question is not so much should universal ART be provided by government but, rather, is it possible to implement in severely resource-constrained environments and, if so, what are the best ways to deliver these services.

The Western Cape public sector ART programme serves as an innovative case study from which to examine this question. In this province, the provincial government launched South Africa's first government-run programme to prevent mother-to-child transmission (PMTCT) of HIV in 1999, and expanded this in 2001 to include ART, making the project the first to use ARVs in government health facilities outside the context of clinical trials. Moreover, in 2004, the pilot ART project was scaled-up throughout the province. It is considered to be a highly effective and successful programme. By December 2005, it was estimated that 55.7% of people that need ART in the province had access to it as compared to a national average of 10% for South Africa.

At the forefront of ART programming, the Western Cape Province provides an important example for the rest of the country on how to successfully scale up HIV/AIDS treatment programmes. It also serves as a pioneering illustration to the global community that the use of ARVs at primary care level in resource-constrained settings is feasible, affordable and replicable. Furthermore, it offers insights into persisting bottlenecks and barriers confronting the rapid roll-out of HIV treatment, the achievement of national targets, and, most importantly, the goal of ensuring long-term universal and, thus, equitable access. As such, drawing from existing literature as well as interviews with key stakeholders, this study examines the factors that have ensured the successful provision and expansion of the ART programme in the Western Cape, as well as the challenges of expanding coverage beyond current levels and building sustainable human resources and health systems to support it.

Glossary of Terms

AIDS	Acquired Immune Deficiency Syndrome
ALP	AIDS Law Project
ARK	Absolute Return for Kids
ARV	Antiretroviral
ART	Antiretroviral Therapy
ASSA	Actuarial Society of South Africa
AU	African Union
CBO	Community-Based Organisation
CHC	Community Health Clinic
DOH	Department of Health
DOTS	Directly Observed Treatment, Short Course
GDP	Gross Domestic Product
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Treatment
HIV	Human Immunodeficiency Virus
HRH	Human Resources for Health
ICESCR	International Covenant on Economic, Social and Cultural Rights
IDU	Injecting Drug User
JCSMF	Joint Civil Society Monitoring Forum
MAP	World Bank Multi-Country HIV/AIDS Programs
MDR-TB	Multi-Drug Resistant Tuberculosis
MSF	Médecins Sans Frontières
MTCT	Mother-To-Child Transmission
NGO	Non-Governmental Organisation
PEPFAR	The US President's Emergency Plan for AIDS Relief
PGWC	Provincial Government of the Western Cape
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother-To-Child Transmission
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TRIPS	Trade Related Aspects of Intellectual Property Rights
TB	Tuberculosis
UCT	University of Cape Town
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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Introduction

Despite countless interventions, HIV/AIDS¹ continues to rise in nearly every region across the globe. 2005 witnessed the highest number of people living with the virus, an estimated 38.6 million [33.4 million-46.0 million], with over four million people newly infected in the last year (UNAIDS, 2006). Sub-Saharan Africa remains the worst affected region and is home to almost two-thirds of all people, and 77% of all women, living with HIV (UNAIDS, 2005). In South Africa, a history of oppression, social disenfranchisement, the migrant labour system and poverty have contributed to the spread of the epidemic with estimated adult prevalence rates of 18.8% [16.8%-20.7%] within a general population of 47.43 million (UNAIDS, 2006). In addition, South Africa continues to have the highest number of people living with HIV in the world estimated at 5.5 million [4.9 million–6.1 million] (*ibid*)². An analysis of death registration data shows a substantial rise in the total number of adult deaths in the past six years -- an increase of more than 40% and, for women aged 20–49 years, an increase of more than 150% taking into account population growth and improvements that have been made in the registrations of deaths (Bradshaw, 2004).

Within this context, there has been a widespread movement advocating for universal access to affordable, quality and lifesaving HIV/AIDS drugs as a critical component in addressing the spread and impact of HIV/AIDS. Antiretroviral Therapy (ART)³ has been shown to make a dramatic difference in the health and survival of People Living with HIV/AIDS (PLWHA), prolonging their lives as active citizens (Farmer *et al.*, 2001; Schneider & Coetzee, 2003; Coetzee *et al.*, 2004a). Specifically, ART has been shown to cause a dramatic drop in the

¹ Commonly denoted merely as these acronyms, HIV stands for the Human Immunodeficiency Virus and AIDS is the Acquired Immune Deficiency Syndrome.

² There has been much debate concerning the accuracy of the UNAIDS models and their underlying assumptions. Using a larger number of variables and inputs, the ASSA Interventions Models engineered at the University of Cape Town have historically estimated prevalence rates as well as PLWHA in South Africa to be somewhat lower. Until 2005, these projections have been more in line with provincial and national estimations suggesting the models' greater accuracy (Abdullah, 2005a; Bourne, 2005; Dorrington *et al.*, 2004). However, in the last year, UNAIDS estimates now have confidence intervals as noted above allowing for these discrepancies in modelling and these now match the national Department of Health estimates (DOH, 2006a).

³ Antiretroviral Therapy (ART) is also known as Highly Active Antiretroviral Therapy (HAART). I will use the term ART for the course of this paper.

number of opportunistic infections and the consequent number of hospital admissions (Farmer *et al.*, 2001; Nattrass, 2004). Research has also demonstrated that when HIV/AIDS treatment programmes are available, accessible and culturally-acceptable to communities, participation in Voluntary Counselling and Testing (VCT) increases (Nattrass, 2004; UNAIDS, 2005; WHO, 2005a). This has two-fold benefits that could contribute to halting the further spread of the epidemic: It enhances prevention efforts among people, whether they have tested negative or positive, and it decreases the potency of the virus in individuals who are HIV positive and undergoing treatment, hence, rendering them less infectious (Abdool Karim *et al.*, 2003; Farmer *et al.*, 2001; Nattrass, 2003)⁴. Moreover, transforming AIDS from a terminal illness into a chronic disease can provide the impetus for overcoming community stigma and discrimination of PLWHA -- further strengthening prevention campaigns (Abdool Karim *et al.*, 2003; Lange *et al.*, 2004; Stein, 2005).

Until recently, the national implementation of a public sector ART programme in South Africa seemed financially impossible (Kovsted, 2005; Nattrass, 2004; Orrell *et al.*, 2003; Robins, 2004). While the cost per patient used to be as high as US\$ 10,000 per year for patented drugs (Kasper *et al.*, 2003), as a result of global activism and generic competition, alternatives are now available for US\$ 156 per person per year (WHO, 2005b). Today, the debate is not so much should universal ART be provided by government (Nattrass & Geffen, 2004) but, rather, is it possible to implement in severely resource-constrained environments and, if so, what are the best ways to deliver these services (WHO, 2005a; WHO, 2006). The Western Cape public sector ART programme serves as an innovative case study from which to examine this question. In this province, the provincial government launched South Africa's first government-run programme to prevent mother-to-child transmission (PMTCT) of HIV in 1999, and expanded this in 2001 to include ART, making the project the first to use Antiretrovirals (ARVs) in government health

⁴ In the context of HIV epidemics in developed nations, there is a school of thought that ART will lead PLWHA to engage in more risky behaviours as HIV/AIDS will be seen more as a chronic disease. Given this, and the fact that infected individuals live longer on treatment, there are scholars who question whether the reduced viral load as a result of treatment outweighs these other factors (Kovsted, 2005). Nattrass (2003) concluded that the evidential base of behaviour studies among men who have sex with men in Canada, Netherlands, Spain, Switzerland and the United States was a context not necessarily transferable to the primarily heterosexual driven epidemic in South Africa (and other African countries). She and other scholars have also found problems of selection bias and shortage of data in these cited studies (Kovsted, 2005; Nattrass, 2003).

facilities outside the context of clinical trials (Abdullah⁵, 2005b). Moreover, in 2004, the pilot ART project was scaled-up throughout the province (*ibid*). It is considered to be a highly effective and successful programme (Abdullah, 2005b; Bekker *et al.*, 2006; Coetzee *et al.*, 2004a; Kasper *et al.*, 2003; MSF & UCT, 2003; Orrell *et al.*, 2003, TAC & ALP, 2004 & 2005; WHO, 2003) as defined by its capacity to quickly and effectively treat a substantial number of people living with HIV/AIDS while yielding measurable reductions in AIDS-related morbidity and mortality (WHO, 2003). By December 2005, it was estimated that 55.7% of people that need ART in the Western Cape had access to it (Nattrass, 2006a) -- compared to a national average of 10% for South Africa as a whole (Abdullah, 2006 quoted by Herman, 2006).

Overview of Dissertation

At the forefront of innovative ART programming, the Western Cape Province provides an important example for the rest of the country on how to successfully scale up HIV/AIDS treatment programmes. It also serves as a pioneering illustration to the global community that the use of ARVs at primary care level in resource-constrained settings is feasible, affordable⁶ and replicable. Furthermore, it offers insights into persisting bottlenecks and barriers confronting the rapid roll-out of HIV treatment, the achievement of national targets, and, most importantly, the goal of ensuring long-term universal and, thus, equitable access. As such, drawing from existing literature as well as interviews with key stakeholders, this study examines the factors that have ensured the successful provision and expansion of the ART programme in the Western Cape, as well as the persisting challenges of expanding coverage beyond current levels and building sustainable human resources and health systems to support it.

⁵ Dr. Fareed Abdullah is the former Deputy Director General and Head of the AIDS programme in the Western Cape Province. He recently departed from this position in January 2006 (Herman, 2006).

⁶ The Health Economics Unit at UCT has done costing studies that demonstrate that per life-year gained, the costs of ART are marginally less than the costs of providing appropriate health care in the absence of ART. Thus, the intervention is considered efficient (Cleary *et al.*, 2004).

Structure of Dissertation

The *first chapter* provides an overview of the global HIV/AIDS pandemic including specifics for the Sub-Saharan Africa region. It considers the importance of access to HIV/AIDS treatment as fundamental to both public health goals and human rights principles. Following, the current state of access to ARVs globally is reviewed. Finally, it elaborates on South Africa's epidemic including the history and politics of national treatment advocacy and provision. A synopsis of South Africa's *National Antiretroviral Treatment Guidelines* is also provided.

The *second chapter* describes the research methodology utilized. It details the research methods used and which informants were selected for this project and why. It also notes any potential constraints and biases in this particular study.

The *third chapter* presents key findings of the critical factors that have contributed to the Western Cape ART programme's success. These include the epidemiology of the epidemic and historically strong health systems in the province, the lesson-building from the PMTCT intervention and pilot ART sites, the successful partnerships that have been cultivated, the strategies that have been utilized to ensure high rates of adherence and the leadership and management model of the programme.

The *fourth chapter* presents key findings of the main challenges confronting the Western Cape ART programme. These include fostering equitable and universal access to ARVs and ensuring health systems strengthening in scaling up the programme. In considering equity, this chapter reflects on the programme's strategies in selecting ART sites and patients, whether both men and women are being appropriately targeted and reached and the programme's nutrition component.

The *conclusion* summarises the main arguments presented in this dissertation.

Other Critical Considerations Outside the Scope of This Study

There are a plethora of other critical issues in ART scale-up that this case study will not elaborate on due to constraints in the length and scope of this paper. *Firstly*, it will consider ARV treatment for adults but will not explicitly detail the progress and challenges in reaching children who are HIV positive. This is a critically important area of study and the omission of this specific topic in no way minimizes its importance.

Secondly, beyond the policy considerations already stipulated in contemplating equity in access to ART, there are a number of other socio-cultural factors that could also affect this and that merit further study. These include an exploration as to how the language of providers as compared to patients affects access and, ultimately, treatment outcomes; how the current disability grant requirements may impede potential patients from accessing ART services; and the role of traditional medicine⁷ vis-à-vis enrolment in the ART programme.

Thirdly, while the success of HIV/AIDS treatment programmes is largely dependent on the effectiveness of HIV/AIDS prevention strategies, due to constraints in space, this study will not elaborate on how the prevention efforts in the province may have facilitated the HIV/AIDS treatment response.

Lastly, treatment protocols, national and global negotiations with pharmaceuticals pertaining to prices of HIV/AIDS drugs, as well as South Africa's patent legislation vis-à-vis the World Trade Organisation's agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS) (1994) deserves dedicated discussion. This is particularly warranted due to the fact that the South African government is still challenged to access cheaper alternatives of certain essential HIV/AIDS medicines through voluntary and compulsory licensing (Geffen, 2001; MSF, 2005). While the researcher is unable to address this complex topic within the span of this dissertation, this critical area in ARV provision ultimately determines the affordability and, thus, the feasibility and sustainability of national roll-out ART campaigns.

⁷ Traditional medicine is "diverse health practices, approaches, knowledge and beliefs incorporating plant, animal and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness" (WHO, 2002:7).

CHAPTER 1: HIV/AIDS, Access to Treatment and South Africa

The Global Context: The HIV/AIDS Pandemic

Since its initial discovery in the early 1980s, HIV and AIDS has continued to rise in nearly all regions every year⁸, resulting in an estimated total of 25 million deaths across the world (UNAIDS, 2005). 2005 witnessed the highest number of people living with the virus, an estimated 38.6 million [33.4 million-46.0 million], with over four million people newly infected in the last year (UNAIDS, 2006). Moreover, in 2005 an estimated 2.8 million [2.4 million-3.3 million] people lost their lives to AIDS (*ibid*). The vast majority (87%) of infections are acquired through heterosexual sex (Abdool Karim, 2005:243), with other modes of transmission including homosexual sex, childbirth, breastfeeding, blood transfusions, injecting drug use (IDU) and exposure to open wounds (Usdin, 2003). While the overall global HIV incidence rate (annual number of new HIV infections as a proportion of previously uninfected persons) peaked in the late 1990s, the number of people living with HIV/AIDS has continued to rise as a result of population growth and, most recently, the introduction of life-saving ARVs (UNAIDS, 2006).

Significantly, the percentage of women infected and affected by HIV/AIDS continues to increase disproportionately (UNAIDS, 2005). Women are not only affected by higher infection rates but also carry the burden of care and support for those with AIDS-related illness (Peacock & Botha, 2004). Sub-Saharan Africa remains the worst affected region and is home to almost two-thirds of all people and 77% of all women living with HIV (UNAIDS, 2005) (see *Figure 1* on the next page). Moreover, young women between the ages of 15 and 24 years living in Sub-Saharan Africa are three times as likely to be HIV positive compared to young men of a similar age (UNAIDS, 2006). Furthermore, in six countries in Southern Africa (Botswana, Lesotho, Namibia, South Africa, Swaziland and Zimbabwe), the prevalence of HIV in pregnant women presenting at antenatal clinics is an astounding 20% or higher (UNAIDS, 2005). In addition, nine in ten children living with HIV live in the region as do 12.0 million [10.6 million-13.6 million] orphans⁹ (UNAIDS, 2006).

⁸ A single exception is in the Caribbean region where the number of people living with HIV did not increase in 2005 (UNAIDS, 2005).

⁹ An orphan is defined as a child of age 0 to 17 years that has lost one or both of parents to AIDS (UNAIDS, 2006).

Notwithstanding the alarming statistics, recent declines in national HIV prevalence rates in Kenya and Zimbabwe and in urban areas in Burkina Faso offer hope for other countries in the region (UNAIDS, 2006). *Figure 2* overleaf provides a sample of current trends in HIV prevalence in the Sub-Saharan Africa region. From this, one can see that the epidemic in South Africa is still increasing as compared to epidemics in other countries.

Country	Adults (15+) and children living with HIV	Adults (15+) and children newly infected with HIV	Adult (15-49) prevalence (%)	Adult (15+) and child deaths due to AIDS
Sub-Saharan Africa				
2005	24.5 million [21.6-27.4 million]	2.7 million [2.3-3.1 million]	6.1 [5.4-6.8]	2.0 million [1.7-2.3 million]
2003	23.5 million [20.8-26.3 million]	2.6 million [2.3-3.0 million]	6.2 [5.5-7.0]	1.9 million [1.7-2.3 million]
North Africa and Middle East				
2005	440 000 [250 000-720 000]	64 000 [38 000-210 000]	0.2 [0.1-0.4]	37 000 [20 000-62 000]
2003	380 000 [220 000-620 000]	54 000 [31 000-150 000]	0.2 [0.1-0.3]	34 000 [18 000-57 000]
Asia				
2005	6.3 million [5.7-12.5 million]	930 000 [620 000-2.4 million]	0.4 [0.3-0.6]	600 000 [400 000-850 000]
2003	7.6 million [5.2-11.3 million]	860 000 [560 000-2.3 million]	0.4 [0.2-0.6]	500 000 [340 000-710 000]
Oceania				
2005	78 000 [48 000-178 000]	7 200 [3500-38 000]	0.3 [0.2-0.8]	3 400 [1900-5500]
2003	66 000 [41 000-140 000]	6 000 [4300-69 000]	0.3 [0.2-0.7]	2 300 [1300-3600]
Latin America				
2005	1.6 million [1.2-2.4 million]	140 000 [100 000-420 000]	0.5 [0.4-1.2]	59 000 [47 000-76 000]
2003	1.4 million [1.1-2.0 million]	130 000 [95 000-310 000]	0.5 [0.4-0.7]	51 000 [40 000-67 000]
Caribbean				
2005	330 000 [240 000-420 000]	37 000 [26 000-54 000]	1.6 [1.1-2.2]	27 000 [19 000-36 000]
2003	310 000 [230 000-400 000]	34 000 [24 000-47 000]	1.5 [1.1-2.0]	28 000 [19 000-38 000]
Eastern Europe and Central Asia				
2005	1.5 million [1.0-2.3 million]	220 000 [150 000-650 000]	0.8 [0.6-1.4]	53 000 [36 000-75 000]
2003	1.1 million [700 000-1.7 million]	160 000 [110 000-440 000]	0.6 [0.4-1.0]	28 000 [19 000-39 000]
North America, Western and Central Europe				
2005	2.0 million [1.4-2.9 million]	65 000 [52 000-98 000]	0.5 [0.4-0.7]	30 000 [24 000-45 000]
2003	1.8 million [1.3-2.7 million]	65 000 [52 000-98 000]	0.5 [0.3-0.6]	30 000 [24 000-45 000]
TOTAL				
2005	38.6 million [33.4-46.0 million]	4.1 million [3.4-6.2 million]	1.0 [0.9-1.2]	2.8 million [2.4-3.3 million]
2003	36.2 million [31.4-42.9 million]	3.9 million [3.3-5.8 million]	1.0 [0.8-1.2]	2.6 million [2.2-3.1 million]

Figure 1 : REGIONAL HIV AND AIDS STATISTICS AND FEATURES, 2003 - 2005 (UNAIDS, 2006)

Country	Median HIV prevalence (%) among women attending antenatal clinics 2003-2004*	Population-based survey prevalence (%) (year)	2003 HIV prevalence (%) reported in 2004 Report on the global AIDS epidemic	Adjusted 2003 HIV prevalence (%) in current report	2005 HIV prevalence (%) in current report	Trend in prevalence
Botswana	38.5	25.2 (2004)	38.0	24.0	24.1	Stable
Burkina Faso	2.5	1.8 (2003)	4.2	2.1	2.0	Decline in urban areas
Burundi	4.8	3.6 (2002)	6.0	3.3	3.3	Decline in capital city
Cameroon	7.3†	5.5 (2004)	7.0	5.5	5.4	Stable
Ethiopia	8.5	1.6 (2005)**	4.4	(1.0-3.5)	(0.9-3.5)	Decline in urban areas
Ghana	3.1	2.2 (2003)	3.1	2.3	2.3	Stable
Guinea	4.2	1.5 (2005)	2.8	1.6	1.5	Stable
Lesotho	28.4	23.5 (2004)	29.3	23.7	23.2	Stable
Rwanda	4.6	3.0 (2005)	5.1	3.8	3.1	Decline in urban areas
Senegal	1.9	0.7 (2005)	0.8	0.9	0.9	Stable
Sierra Leone	3.0	1.5 (2005)	-	1.6	1.6	Stable
South Africa	29.5	16.2 (2005)	20.9	18.6	18.8	Increasing
United Republic of Tanzania	7.0	7.0 (2004)	7.0	6.6	6.5	Stable
Uganda	6.2‡	7.1 (2004-5)	4.1	6.8	6.7	Stable

Figure 2 : ADULT HIV PREVALENCE (%) IN COUNTRIES IN SUB-SAHARAN AFRICA WHICH HAVE CONDUCTED POPULATION-BASED HIV SURVEYS IN RECENT YEARS (UNAIDS, 2006)

Access to HIV/AIDS Treatment: The Integration of Public Health and Human Rights Approaches

While traditionally separate fields, in the face of the burgeoning HIV/AIDS pandemic scholars have pioneered the integration of Public Health and Human Rights approaches. Stemming from the leadership of the late Jonathan Mann who headed the first Global Programme on HIV/AIDS at the World Health Organisation (WHO), WHO's strategy for addressing the further spread of HIV has encouraged promoting and protecting the rights of PLWHA and has excluded traditional coercive practices of isolation and quarantine that have been utilized for addressing, for example, small pox (Mann *et al.*, 1999). Specifically, these approaches aim at attaining public health goals while simultaneously promoting and protecting rights. This inextricable link between Health and Human Rights originates from the recognition that attaining Health and Rights are complementary to achieving human well-being. This was first articulated in Article 25 of the Universal Declaration of Human Rights (UDHR) (1948) and more elaborately later in Article 12 of the International Covenant on

Economic, Social and Cultural Rights (ICESCR) (1966). Specifically, Article 12(c) of the ICESCR empowers governments to take the necessary steps for prevention, treatment and control of epidemic, endemic, occupational and other diseases (Gruskin & Tarantola, 2002). Building upon these internationally-recognized legal frameworks, Mann *et al.* (1999:17) noted that:

“The evolving HIV/AIDS pandemic has shown a consistent pattern through which discrimination, marginalization, stigmatization, and, more generally, a lack of respect for the human rights and dignity of individuals and groups heighten their vulnerability to becoming exposed to HIV”.

Therefore, in order to reduce the vulnerability of individuals and groups to the virus and, thus, effectively halt the spread of HIV, human rights frameworks should form the foundation of all HIV/AIDS public health interventions (*ibid*). Moreover, a human rights-based approach to addressing the enormous impact of HIV/AIDS on public health is the only realistic option for an epidemic concentrated in poor and marginalised communities, most of which don't have adequate access to health care or the ability to pay for treatment (Mukherjee, 2004).

Building upon the UDHR -- which was ratified by over 140 countries -- the debate on access to treatment for HIV/AIDS has been fuelled against both governments and pharmaceutical companies in the name of human rights (Geffen, 2001). This has included a global grassroots demand for states to meet their obligations to respect, promote, protect and, most importantly, fulfil the rights to life, dignity, equality, information, education, participation, bodily integrity, scientific progress, non-discrimination, and, more specifically, the right to health, including health care. The right of *everyone* to the “enjoyment of the highest attainable standard of physical and mental health” (ICESCR, 1966: Article 12, General Comment 14) has four criteria:

- 1) Availability (of sufficient services);
- 2) Accessibility (physically, economically, culturally and in terms of information);
- 3) Acceptability (within medical ethics and culturally-appropriate); and
- 4) Quality (goods and services must be scientifically sound).

Hence, national HIV/AIDS treatment plans must seek to meet these standards to fulfil state duties to individuals in the right to health. Significantly, Gruskin and Tarantola (2002) note

that public health measures addressing HIV/AIDS that fail to consider other valid and less restrictive alternatives -- such as the provision of lifesaving HIV/AIDS drugs -- can be considered not only abusive to human rights principles but also to public health best practice. Thus, instead of the traditional dichotomous positioning of public health interventions versus human rights approaches, ensuring access to ART enables governments to meet both their public health goals in halting the spread and impact of the HIV/AIDS epidemic, as well as their human rights duties to citizens.

Access to Antiretroviral Therapy: A Global Overview

With the promise of transformation of HIV/AIDS from a terminal to a chronic illness, access to ART has been high on the global agenda. (See *Appendix A* for details on the workings of the HIV retrovirus and ART). This was evidenced at the historic United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in 2001. Here, the Declaration of Commitment on HIV/AIDS was adopted by leaders from 189 Member States committing them to targets for the delivery of HIV prevention, treatment, care and support programmes needed to halt and begin to reverse the global epidemic by 2015 (UNAIDS, 2006). Moreover, access to affordable, quality and life-saving HIV/AIDS drugs is considered one of the most pertinent challenges in addressing the spread and impact of HIV/AIDS, and in fulfilling the UNGASS goals as well as the Sixth Millennium Development Goal¹⁰. Two key viewpoints are fuelling the momentum to rapidly scale-up public sector ART campaigns: The promotion and fulfilment of international, regional and national human rights obligations as well as the beneficial effects that access to treatment has on HIV/AIDS patients, overall prevention campaigns and, ultimately, the spread of the epidemic. While ART is widely available in developed countries, access to HIV/AIDS treatment is inadequate in low and middle income countries.

In this context, in 2001, the UN Secretary General and world leaders called for the creation of a global fund to fight AIDS. In 2002, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) was launched as a private-public partnership aimed primarily at financing life-saving treatment efforts for the three diseases. Other bilateral and

¹⁰ Adopted in 2000 by UN Member States the Millennium Development Goals are a set of global targets for reducing poverty and extending universal rights by 2015 (UNDP, 2005).

multilateral support for treatment has also increased in response to WHO's "3 by 5" campaign launched in 2003 aiming to provide ART to 3 million PLWHA in low and middle income countries by the end of 2005. While this campaign far from reached its target, access to ARVs in resource-poor contexts has greatly increased largely due to the GFATM, the World Bank's Multi-Country HIV/AIDS Programs (MAP) and the U.S. President's Emergency Plan For AIDS Relief (PEPFAR) (UNAIDS, 2006). However, despite the availability of financial resources, and drastically reduced generic prices, many countries are struggling to roll-out treatment campaigns in the face of numerous infrastructure and systems barriers as well as socio-economic inequalities (WHO, 2005a). Most countries in Africa report that the demand for treatment is surpassing their capacity to supply it (*ibid*). Currently, 20% of the people who need HIV/AIDS medicines in low and middle income countries have access to them (WHO, 2006).

This situation has sparked a renewed advocacy campaign to ensure access to HIV/AIDS treatment in poor countries. In 2005, commitments towards achieving universal access to treatment for all those who need it by 2010 were re-affirmed at the Gleneagles summit of the G8 industrialized nations and at the World Summit meeting held in September 2005 at the United Nations Headquarters (UNAIDS, 2006). This spirit was further echoed within the Africa region at the recent Special Summit for the African Union (AU) on HIV/AIDS, Tuberculosis and Malaria in May 2006 (AU, 2006).

Amidst these global and regional advocacy efforts, there have been pockets of success in scale-up in the last two years. By the end of 2005, the number of people accessing ART in developing countries increased from 400,000 in 2003 to 1.3 million (UNAIDS, 2006). *Figure 3* on the next page shows the regional distribution of this ART coverage, including the estimated number of people receiving and needing ART between December 2003 and 2005. Notably, in the Sub-Saharan Africa region, scale-up to ART has been dramatic with an estimated 810,000 people on treatment in 2005 as compared to 100,000 in 2003. *Figure 4* diagrammatically represents this rapid rise in coverage in the region. This sharp increase is attributable to a handful of countries, namely, Botswana, Kenya, South Africa, Uganda and Zambia (*ibid*). While WHO and UNAIDS recently estimated that only one out of six people of the 4.7 million people who need ART in Sub-Saharan Africa now receive it, significantly, South Africa accounts for 25% of all PLWHA on ART in the region (*ibid*).

Geographical region	Estimated number of people receiving antiretroviral therapy, December 2005 [low estimate–high estimate] ^b	Estimated number of people 0–49 years old needing antiretroviral therapy, 2005 ^a	Antiretroviral therapy coverage, December 2005 ^c	Estimated number of people receiving antiretroviral therapy, December 2004 [low estimate–high estimate] ^b	Estimated number of people receiving antiretroviral therapy, December 2003 [low estimate–high estimate] ^b
Sub-Saharan Africa	810 000 [730 000–890 000]	4 700 000	17%	310 000 [270 000–350 000]	100 000 [75 000–125 000]
Latin America and the Caribbean	315 000 [295 000–335 000]	465 000	68%	275 000 [260 000–290 000]	210 000 [160 000–260 000]
East, South and South-East Asia	160 000 [150 000–210 000]	1 100 000	16%	100 000 [85 000–115 000]	70 000 [52 000–88 000]
Europe and Central Asia	21 000 [20 000–22 000]	160 000	13%	15 000 [3 000–17 000]	15 000 [11 000–19 000]
North Africa and the Middle East	4 000 [3 000–5 000]	75 000	5%	4 000 [2 000–6 000]	1 000 [750–1 250]
Total	1 330 000 [1 200 000–1 460 000]	6 500 000	20%	700 000 [630 000–770 000]	400 000 [300 000–500 000]

Figure 3 : ESTIMATED NUMBER OF PEOPLE RECEIVING AND NEEDING ART AND PERCENTAGE COVERAGE IN LOW AND MIDDLE INCOME COUNTRIES BY REGION, DECEMBER 2003–DECEMBER 2005. (WHO, 2006)

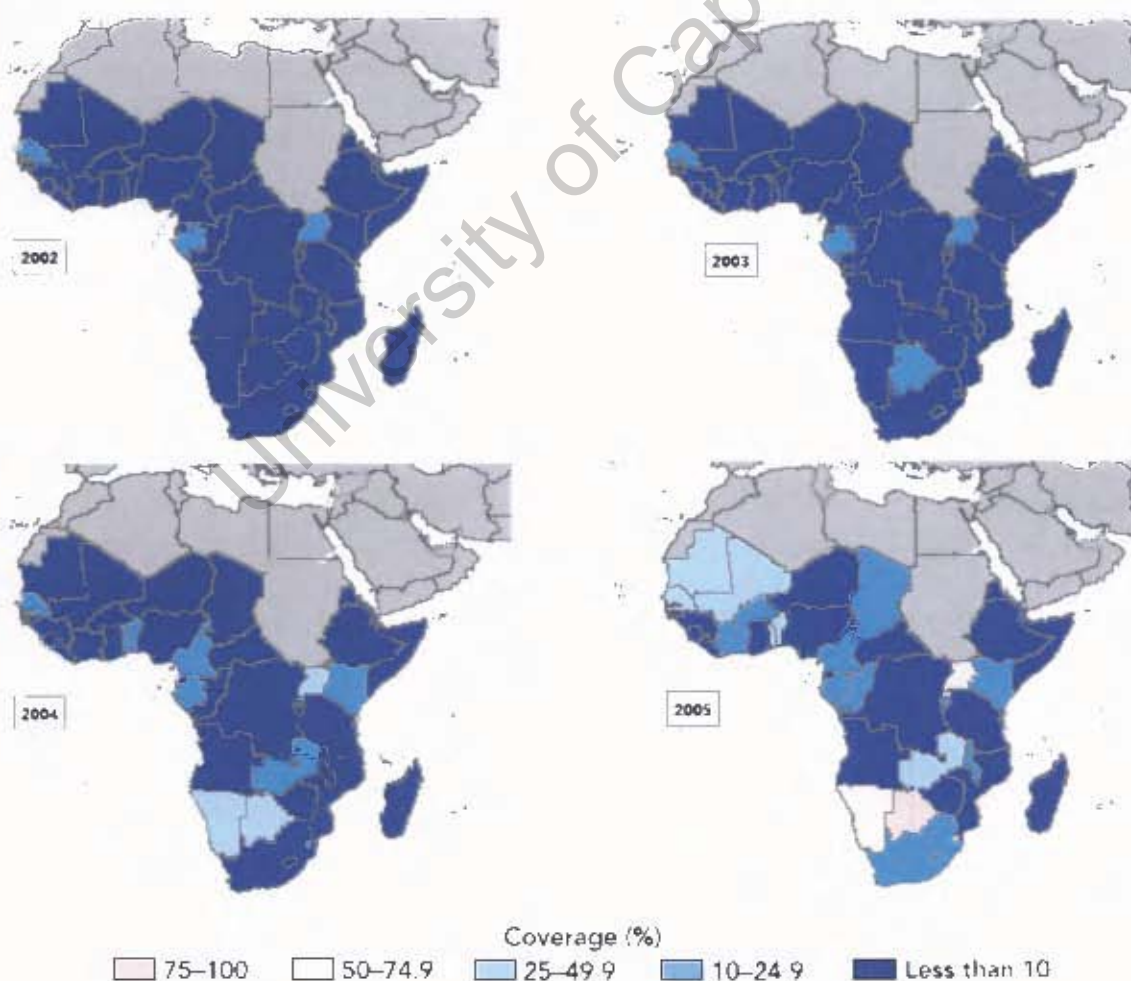


Figure 4 : PEOPLE IN SUB-SAHARAN AFRICA ON ART AS PERCENTAGE OF THOSE IN NEED, 2002–2005. (WHO, 2006)

HIV/AIDS and Treatment in South Africa

South Africa's HIV/AIDS Epidemic

One of the worst affected countries in the world, South Africa's HIV/AIDS epidemic is still on the increase (UNAIDS, 2006). In 2005, an estimated 5.5 million [4.9 million–6.1 million] South Africans were living with HIV and there was an estimated adult (15-49 years) prevalence rate of 18.8% [16.8%–20.7%] (DOH, 2006a; UNAIDS, 2006)¹¹. Moreover, in the last 15 years, prevalence rates of pregnant women presenting at antenatal clinics have risen dramatically from a low 0.7% in 1990 to 30.2% in 2005 -- with some areas showing more than one out of three pregnant women testing positive for HIV (DOH, 2006a) (See Figure 5). Prevalence is highest among women aged 25–34 years (*ibid*) (See Figure 6 on the next page).



Figure 5 : NATIONAL HIV PREVALENCE TRENDS AMONG ANTENATAL CARE ATTENDEES IN SOUTH AFRICA, 1990-2005. (DEPARTMENT OF HEALTH, 2006A)

¹¹ Using mathematical models, estimations are based on South Africa's antenatal clinic surveillance system, national surveys with HIV testing, household surveys and mortality data from the civil registration system (Dorrington *et al.*, 2001; UNAIDS, 2006)

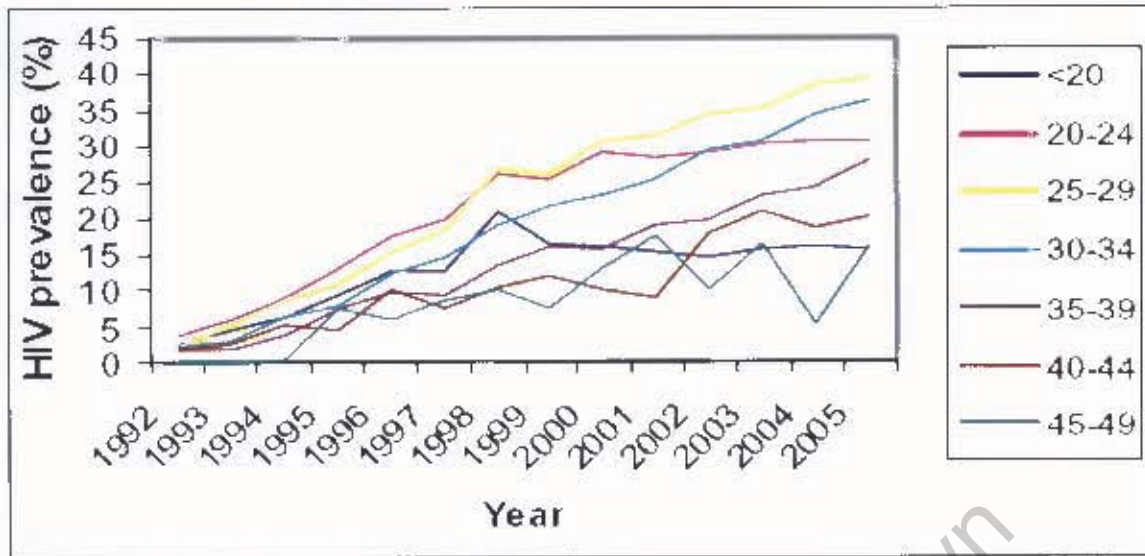


Figure 6 : HIV PREVALENCE TRENDS BY AGE GROUP AMONG ANTENATAL CLINIC ATTENDEES, SOUTH AFRICA: 1991 – 2004. (DEPARTMENT OF HEALTH, 2006A).

In the country's worst-affected province, KwaZulu-Natal, antenatal prevalence has reached over 39%. while it has remained exceptionally high at between 29% and 35% in the Eastern Cape, Free State, Gauteng, Mpumalanga and North West provinces (*ibid*). (See Figure 7 below for a map of South Africa noting the different provinces).



Figure 7 : MAP OF SOUTH AFRICA SHOWING THE NINE PROVINCES.

South Africa also remains the country with the highest number of people infected with HIV, and HIV/AIDS has become the primary cause of death in the nation for both males and females (MRC, 2003). Furthermore, the recently released 2003-2004 mortality report points to some alarming changes in mortality statistics that are attributable to the epidemic. For one, deaths among women have increased 93% between 1997 and 2003 compared to a 60% increase among males in the same period (Statistics South Africa, 2006). In addition, in 2003, for the first time ever, people aged 30-34 years were dying in larger numbers than people in their 60s (*ibid*).

National Context: Treatment Advocacy and Provision

Despite South Africa's ratification of key international and regional agreements that render the government accountable in upholding its human rights obligations, as well as a Constitution that creates an enabling human rights environment for policy formulation and implementation (Government of the Republic of South Africa, 1996; UNHCHR, 2004), access to ART in South Africa has been marred with political controversy and side-stepping. Government's reluctance to develop an HIV/AIDS treatment policy instigated a demand for access to ART that ripened into a social movement, primarily led in the public domain by the Treatment Action Campaign (TAC), a Non-Governmental Organisation (NGO) formed in 1998 with headquarters in Cape Town¹². Drawing upon international and regional human rights instruments as well as the South African Bill of Rights, TAC has used explicit human rights and legal arguments to pressure the Government of South Africa to provide HIV/AIDS treatment (TAC, 2003, 2004 & 2005a).

In early 2001, in a move to quell activist voices, the South African government announced that selected hospitals would offer PMTCT (Van der Vliet, 2004). However, by July 2001 this decision had still not been implemented and some government officials were arguing that initiating PMTCT was not an effective, sustainable and affordable government policy (*ibid*). In April 2002, in an ensuing legal battle between TAC and the Department of

¹² There have been many other key actors in this advocacy effort including academics, health care providers, civil society organisations as well as some Government representatives at different levels. I am highlighting the Treatment Action Campaign in particular because their efforts have included mass grassroots mobilization and activism that has been well documented both nationally and internationally (Butler, 2005; Friedman & Mottiar, 2005; Heywood, 2004; Leclerc-Madlala, 2005; Robins, 2004). Moreover, as an organisation, they have propelled the South African Government as well as pharmaceutical companies into action on this issue through legislative means (*ibid*).

Health (DOH), the Constitutional Court ordered government to provide drugs for the PMTCT of HIV at all public health-care facilities in South Africa (Abdool Karim, 2004). The following year, in October 2003, the government finally heeded the calls by activists for provision of free ART at the national level and announced an Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment (DOH, 2003). This represented the final part of South Africa's multi-sectoral National Strategic Plan for HIV and AIDS (2000-2005) (Marshall, 2004).

This Operational Plan aims to ensure universal, equitable and sustainable implementation by all levels of government; quality of care including the safe use of medicines; strengthening of the National Health System; reinforcing of the government's prevention and nutrition strategies; provision of an accountable continuum of care and treatment; promotion of individual choice of treatments as well as healthy lifestyles; and an integrated response to HIV and Tuberculosis (TB), including Multi-Drug Resistant Tuberculosis (MDR-TB) (DOH, 2003). The programme plans to distribute ART through service points in every local municipality within five years, aiming to treat 1.2 million people¹³ by 2008 (Marshall, 2004). In no other country has an HIV/AIDS treatment plan attempted to reach such large numbers of people (Ncayiyana, 2004). Moreover, in order to assess a service point's capacity to successfully implement ART, the Operational Plan outlines 23 requirements that each site must meet in order to be accredited to provide ARVs. These include, for example, a service point manager; a trained team on site which includes clinicians, nurses, counselors, dieticians, social workers, pharmacists; and links with NGOs in the service area (DOH, 2003:98-100). While a national team is accountable for the accreditation process, the Provincial Departments of Health are responsible for projecting provincial needs for ART as well as locations of service points -- while ensuring equitable access to this service (*ibid*).

¹³ It is important to note that simply initiating people on treatment and, hence, reaching target numbers does not necessitate reduction in viral replication and positive health outcomes in patients if they don't adhere to medications. The 'numbers drive' to ensure large numbers of people on therapy must not be at the expense of long-term quality medical care and patient support to ensure adherence (Kovsted, 2005). Moreover, Prof. Wood of the Desmond Tutu HIV Centre notes that merely monitoring the head count of people on treatment as well as clinical analysis of those on ART does not adequately measure the impact of ART programmes on morbidity and mortality at the population level (Wood, 2006, personal comm., 7 August). Recent research in South Africa -- on the brink of being published -- indicates that 50% of people living with AIDS die before even receiving a diagnosis (*ibid*).

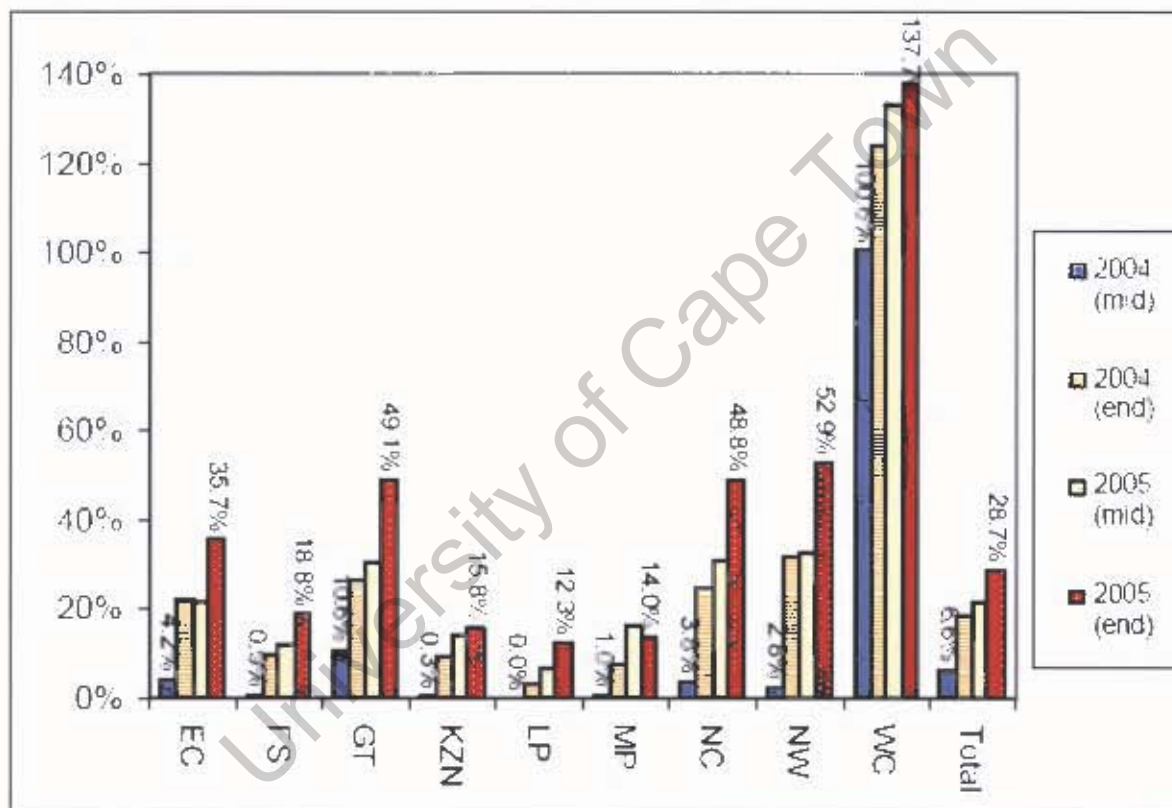
Since 2004, provincial rollout has been slow largely due to delays in obtaining accreditation for treatment sites, shortages in supplies of ARVs, poor information dissemination campaigns and a lack of clear national direction in technical and methodological issues that arise in implementing the plan (Abdool Karim & Abdool Karim, 2005; Abdullah, 2005a & 2005b; TAC & ALP, 2004 & 2005). While *National Antiretroviral Treatment Guidelines* have been developed (DOH, 2004), other important national policy directives are still needed to ensure the effective and equitable implementation of the Operational Plan across all provinces. This includes, but is not limited to, appropriate guidance on testing, nutrition, prevention and training and support of health-care personnel (Abdool Karim, 2004). Furthermore, while a country plan for Human Resources for Health (HRIH) was recently released in April by the national DOH, there has been little consultation with stakeholders regarding its implementation vis-à-vis scaling up ART (ITPC, 2006). While South Africa is faring better than other countries in the region in this regard (see *Figure 8* below), human resource shortages in relation to workload for HIV/AIDS treatment and care persist as one of the key challenges in implementation of the Operational Plan¹⁴.

	Medical doctors per 100,000 population	Nurses per 100,000 population	PLWHA: in thousands	Total population in thousands	PLWHA: per 100,000 population	PLWHA: per medical doctor	PLWHA: per nurse
Malawi	1	26	900	12,105	7,435	7,435	286
Mozambique	2	29	1,300	18,563	6,592	3,446	328
Zimbabwe	6	34	1,530	12,535	14,024	2,337	260
Tanzania	2	37	1,600	36,577	4,327	2,164	117
Rwanda	3	21	250	8,387	2,951	1,490	142
Zambia	7	113	920	10,512	8,509	1,216	75
Swaziland	18	320	220	1,077	20,427	1,135	64
Botswana	29	241	350	1,755	19,606	676	51
Uganda	2	34	530	26,699	1,965	397	37
South Africa	69	388	5,300	45,026	11,771	171	30
Cambodia	16	61	170	14,144	1,202	75	20
Thailand	30	162	570	62,533	907	30	6
Brazil	206	52	660	178,470	370	2	7

Figure 8 : DOCTORS AND NURSES AVAILABLE AND PLWHA IN SELECTED COUNTRIES. (VAN DAMME & KEGELS, 2006 QUOTED BY KOBER & VAN DAMME, 2006).

¹⁴ Boulle, 2006, personal comm., 27 July; Goemaere, 2006, personal comm., 18 July; Grimwood, 2006, personal comm., 10 July; Hassan, 2006, personal comm., 11 July; Maartens, 2006, personal comm., 29 June; Mthathi, 2006, personal comm., 17 July; Toms, 2006, personal comm., 13 July.

Nevertheless, within the framework of the existing national ARV guidelines, each province has been allocated funds by national government for implementation and has developed its own system of delivery. Some provinces have successfully forged ahead with implementation, such as in the Western Cape and Gauteng, while others like the Free State, Limpopo and Mpumalanga have had a stalled start (DOH, 2006b; Nattrass, 2006a; Ndlovu & Daswa, 2006a; TAC & ALP, 2005). *Figure 9* below depicts provincial ART roll-outs as compared to the Operational Plan targets. This clearly shows that, unlike other provinces, the Western Cape has met and even exceeded its treatment targets in 2004 and 2005.



Sources: ASSA 2003 demographic model; Department of Health 2003 and Hassan and Bosch 2006.

Figure 9 : PROVINCIAL ART ROLLOUT AS A PERCENTAGE OF THE OPERATIONAL PLAN TARGET. (NATTRASS, 2006A).

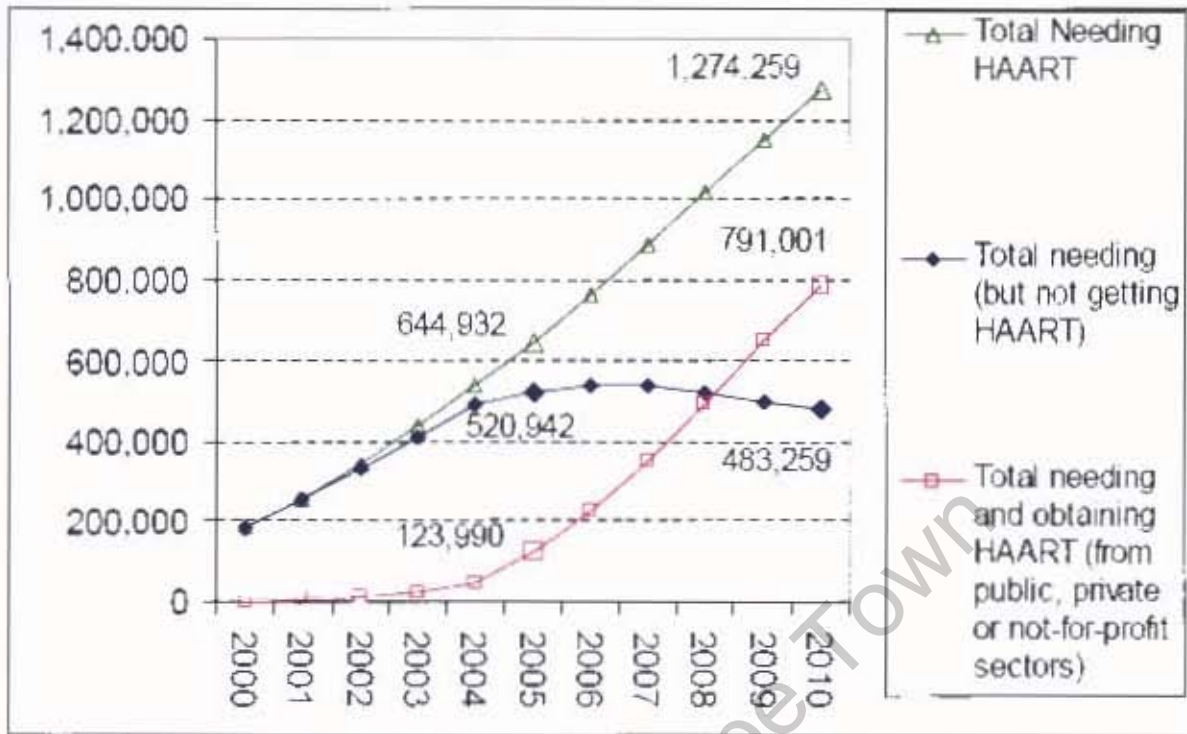
Furthermore, across the country, by the end of December 2005, 204 facilities were providing ART services, with all 53 health districts having at least one health facility providing ART and 63% of the 252 sub-districts having full coverage (DOH, 2006b). *Figure 10* on the next page shows the number of health districts and operational ART health facilities by province:

Province	Number of Health Districts	Operational Health Facilities, End December 2005
Eastern Cape	7	20
Free State	5	5
Gauteng	6	29
KwaZulu-Natal	11	54
Limpopo	6	23
Mpumalanga	3	12
Northern Cape	5	11
North West	4	8
Western Cape	6	42
TOTAL:	53	204

Figure 10 : NUMBER OF HEALTH DISTRICTS AND OPERATIONAL ART HEALTH FACILITIES BY PROVINCE, END DECEMBER 2005. (DEPARTMENT OF HEALTH, 2006b).

Despite the great discrepancies between provinces in ART roll-out as noted above, South Africa has succeeded in scaling-up treatment numbers nationally. Of the approximately 800,000 people living with HIV/AIDS in South Africa and requiring treatment (Nattrass, 2006a), as of June 2006, approximately 140,000 patients were on ARVs through the public system in all nine provinces (JCSMF, 2006b) as compared to a mere 2,000 people in October 2003 (Nattrass, 2006a)¹⁵. Moreover, an additional 90,000 people are estimated to be receiving treatment through private sector sources (JCSMF, 2006a). Nonetheless, this means that fewer than 30% percent of South Africans who need ART are accessing it (see *Figure 11* on the next page). A recent econometric analysis of the determinants affecting ART coverage indicated that South Africa's implementation has been relatively poor given its economic, institutional and epidemiological attributes (Nattrass, 2006b). Amidst the uphill challenge of achieving universal access to treatment, persisting conflicting messages from the Minister of Health about the efficacy and effectiveness of ART vis-à-vis nutritional supplements have also plagued communities with confusion as to how and whether to seek treatment (Nattrass, 2006c; Ndlovu & Daswa, 2006a; Opic, 2005).

¹⁵ Please note that due to the persisting lack of a national monitoring and evaluation system for ART provision, the national Department of Health has noted that the total number of patients receiving ART through the public sector is "not yet known ... in a reliable manner" (IIPC, 2006:34).



Source: ASSA2003 demographic model.

Figure 11 : NUMBERS OF PEOPLE NEEDING AND OBTAINING ART (MID POINTS FOR EACH YEAR) WHETHER FROM THE PUBLIC OR PRIVATE SECTORS. (NATURASS, 2006A).

National Antiretroviral Treatment Guidelines

It is important to understand the policy directions offered by the *National Antiretroviral Treatment Guidelines* for this case study. While WHO (2004a) recommends triple combination first-line ARV therapies for the long-term treatment of adults and adolescents, there is still much debate over when exactly to initiate treatment (Kovsted, 2005; Wood, 2005). The South African *National Antiretroviral Treatment Guidelines* have dictated the following clinical criteria for adults to be eligible for ART through the public sector system: The patient must either have a CD4+ cell count of less than 200 cells/mm³ irrespective of the WHO stage of illness, or must be in WHO stage IV of HIV disease irrespective of the CD4+ count (DOH, 2004:2)¹⁶. Furthermore, there are special considerations for women of childbearing age or who are pregnant, children, people with HIV and TB co-infection and IDUs (DOH, 2004).

In addition to clinical eligibility, the treatment guidelines also specify psychosocial criteria for consideration when selecting a patient for ART (DOH, 2004:3):

- *“Demonstrated reliability, i.e. patient has attended three or more scheduled visits to an HIV clinic;*
- *No active alcohol or other substance abuse;*
- *No untreated active depression;*
- *Disclosure: it is strongly recommended that patients have disclosed their HIV status to at least one friend or family member OR have joined a support group.*
- *Insight: patients need to have accepted their HIV-positive status. They need to have insight into the consequences of HIV infection and the role of ART before commencing therapy.*
- *Patients should be able to attend the antiretroviral centre on a regular basis or have access to services that are able to maintain the treatment chain. Transport may need to be arranged for patients in rural areas or for those far away from the treatment site.”*

¹⁶ Prof. Wood of the Desmond Tutu HIV Centre observes that there are many persisting challenges regarding medical eligibility for ART in South Africa. For one, most people do not know their HIV status let alone CD4+ count to qualify for treatment. With the exception of mothers captured through the PMTCT programme in antenatal clinics, most PLWHA are referred to ART sites when they are already very sick with AIDS. Some believe that there is a need to re-think the HIV/AIDS programme to incorporate VCT Plus sites that allow for counselling and testing as well as CD4+ counts -- enabling eligible patients to be identified and begin treatment earlier on (Wood, 2006, personal comm., 7 August).

These criteria aim to ensure that patients are ready to adhere to this life-long daily treatment. They are not intended to be exclusionary and the final decision is supposed to be taken by a multi-disciplinary team at the ART centre in conjunction with the patient or caregiver. Figure 12 below shows the HIV management flowchart that health practitioners use to guide them in making HIV/AIDS treatment decisions with the patient.

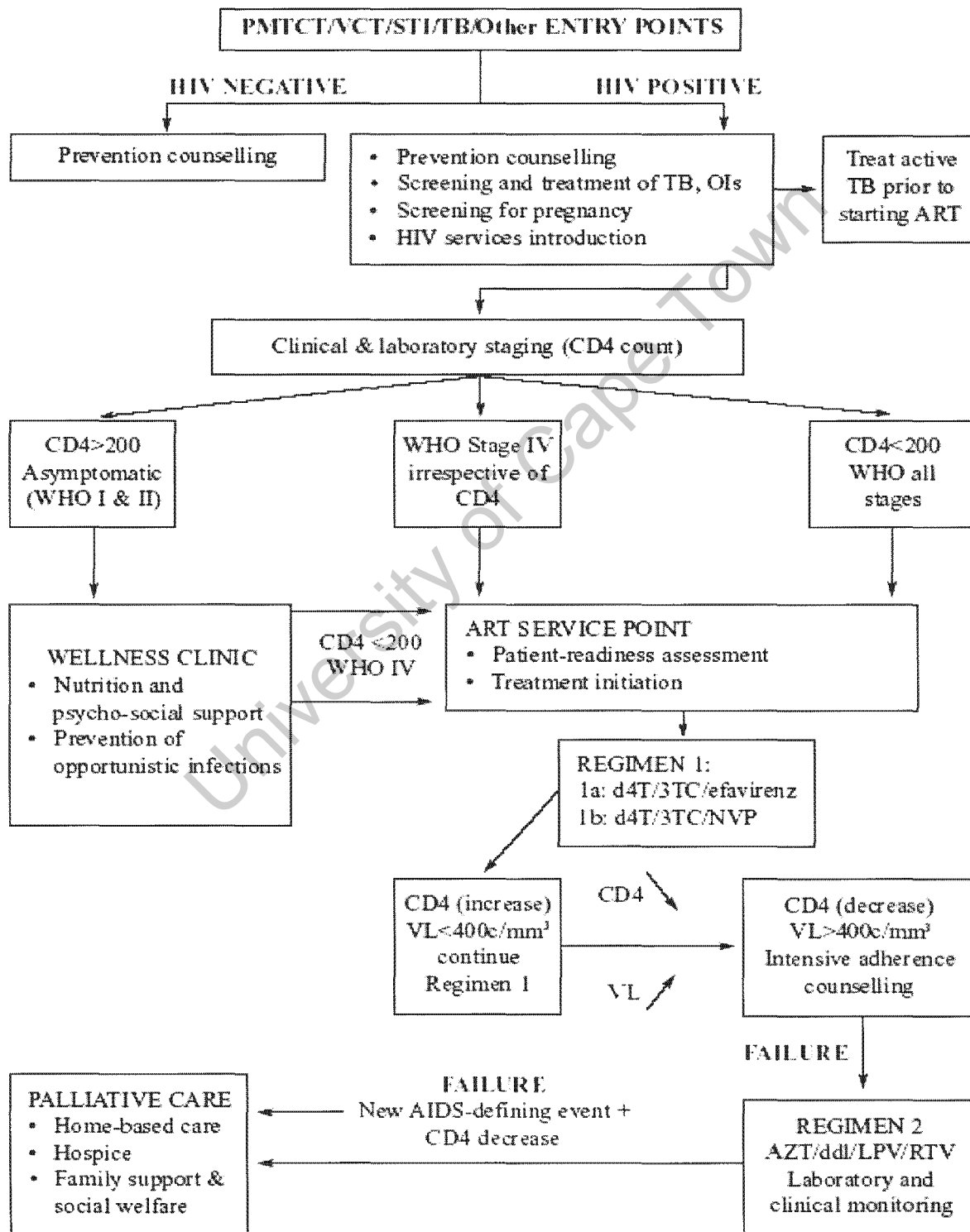


Figure 12 : ADULT HIV MANAGEMENT FLOWCHART. (DEPARTMENT OF HEALTH, 2004)

CHAPTER 2: Methodology

Overview

In the context of a burgeoning HIV/AIDS epidemic, the recent national government's HIV/AIDS treatment plan, combined with an injection of both national and international financial resources and falling prices of HIV/AIDS drugs, has paved the way for national scale-up of ART in South Africa. The Western Cape Province serves as an important example to other provinces as well as the global community that ART programmes implemented at the primary care level in resource-poor contexts can be feasible, effective and, importantly, replicable. This research study explores the success factors and persisting challenges in the public sector ART roll-out in the Western Cape, and takes the form of a case study. Specifically, it examines key aspects contributing to the programme's documented success in reaching large numbers of people who need ART and in ensuring positive health outcomes and survival rates. In addition, it considers continuing challenges confronting the programme in reaching the target of universal access to ART as well as in ensuring health systems strengthening at the primary care level. The level of analysis in this study is at the provincial policy/programmatic level (meso), examining provincial strategies that are determining the health outcomes for people who need ART in the Western Cape.

Using such a case study approach permits an in-depth examination of the specific context of the Western Cape Province, allowing for valuable insights and lessons to be illuminated. While it is not possible to adequately extrapolate conclusions from a single case study, it is hoped that this work will generate some research questions and policy directions that can be further pursued within the Western Cape as well as in other provinces. Moreover, with the roll-out of ART being a recent global endeavour, there is still a dearth of literature on how developing countries are *successfully* implementing ART programmes as well as how they are finding entry points to address challenges in this area. The researcher hopes that this work can also generate ideas for other low and middle income countries that are experiencing similar challenges in the roll-out of public sector HIV/AIDS treatment campaigns.

Research Methods

The following research methods were used in this study:

- Literature review;
- Qualitative research design;
- Interviewing and analysis; and
- Thematic analysis.

In formulating valid arguments for this dissertation, a process of triangulation was used. This involved cross-checking findings from the interviews with published literature -- where it exists -- to ensure the validity of claims.

Interview Process and Case Data Collection

Formal interviews were conducted in the period of June to August 2006 with 16 individuals and these form the primary research for this dissertation. Given that this study's level of analysis is at the meso level, informants were sought at the management level of the ART programme. More specifically, key stakeholders were targeted including the Provincial and City of Cape Town Departments of Health, important implementing NGOs working with the provincial government in delivery of the public-sector ART programme, key academics/clinicians who have been instrumental in the roll-out process in the province, as well as treatment advocacy 'government watch-dog' organisations. The general assumption guiding this strategy is that programme managers have an informed understanding of policy implementation and of patient-oriented challenges.

Qualitative interviews were conducted and were semi-structured in nature asking key questions to all interviewees about the success factors and challenges in the Western Cape ART roll-out. Additional questions were also formulated for each particular informant based on their area of expertise. Interviewees were encouraged to talk freely around these questions and contribute other information that they felt was important to this study. The findings from these interviews, combined with the research from the literature, form the basis of Chapters Three and Four of this dissertation.

Informants

Provincial Department of Health

Dr. Keith Cloete: Provincial Director for HIV/AIDS, Sexually Transmitted Infections (STIs) and Tuberculosis (TB) and Acting Chief Director for District Health Services and Programmes. In this role, Dr. Cloete is responsible for the ART programme in the Province. A public health expert, Dr. Cloete has held numerous senior public health positions and has been working in the Western Cape for many years.

Dr. Nevilene Slingers: Provincial ARV Programme Manager. Dr. Slingers is responsible for overseeing implementation of the ARV programme and for human resource management for treatment provision. In this role, she manages all the dedicated ARV clinics in the Province. Dr. Slingers has been working for the public health sector for many years and has held various positions, particularly within primary health care service delivery.

Ms. Meg Osler: Co-ordinator of the ARV Monitoring and Evaluation Programme of the Provincial Department of Health. Ms. Osler is responsible for improving systems in all Western Cape ART sites to enable effective outcome-based monitoring and evaluation of the ART programme.

Ms. Luzette Van Nierkerk: Assistant Director of the Integrated Nutrition Programme, Comprehensive Health Programmes of the Provincial Department of Health. In this role, Ms. Van Nierkerk is responsible for the following key areas: Disease-specific nutrition support, treatment and counselling including for HIV/AIDS patients, micronutrient malnutrition control and food service management. This includes coordinating with the HIV/AIDS Directorate in provision of supplemental nutrition for ART patients that are food insecure.

City of Cape Town Department of Health

Dr. Ivan Toms: Director of Health of the City of Cape Town Department of Health. Dr. Toms is responsible for Primary Health Care and oversees all city health programmes including the HIV and TB programmes. He founded Empilisweni SACLA Clinic which is responsible for training community health workers. Dr. Toms also became a National Co-ordinator for Service Development in 1990 and has served as a Director for a number of health service structures.

Dr. Pren Naidoo: Director of HIV/AIDS and TB of the City of Cape Town Department of Health. Dr. Naidoo is responsible for overseeing and coordinating ARV treatment provision and supporting services offered in the Cape Town metropolitan area.

Implementing Partners

Dr. Eric Goemaere: Head of Mission of Médecins Sans Frontières (Doctors without Borders) in South Africa. Dr. Goemaere provided technical assistance to the Western Cape Department of Health in running their first PMTCT programme in 1999 in Khayelitsha. In 2001, he also set up the first pilot ART site in South Africa in the Western Cape Province within a government-run primary health care setting -- also in Khayelitsha. He has vast experience as an HIV practitioner and a wealth of knowledge on successfully expanding provision of ART within an urban resource-poor context. In partnership with the Provincial Department of Health, he continues to oversee all existing three ART sites in Khayelitsha.

Dr. Ashraf Grimwood: Executive Director of Absolute Return for Kids (ARK) in South Africa, an international (U.K.-based) NGO. A clinician himself, Dr. Grimwood has years of expertise as an HIV practitioner both within the private and public sector and has been a key stakeholder in supporting the roll-out of ART within the Western Cape Province. Before ARK, he served as Director of the South Africa HIVAC Medical Research Council since 2002, and Director of the Bristol-Myers Squibb (BMS) HIV/AIDS Research Institute in South Africa preceding this. In August 2003, Dr. Grimwood was appointed by the South African President to the 16-member South African Aids Task Team responsible for the development of the detailed plan to roll out anti-retroviral treatment for the country. He is also a contributor to the *National Antiretroviral Treatment Guidelines*.

Ms. Anita Jason: Patient Advocate Programme Manager of Absolute Return for Kids (ARK) in South Africa. Ms. Jason has expertise as a community liaison manager and in developing strategies to ensure adherence in delivery of ART in the Western Cape and KwaZulu-Natal provinces.

Professor Robin Wood: Director of the Desmond Tutu HIV Centre, Institute for Infectious Disease and Molecular Medicine, University of Cape Town and a Professor of Medicine. The Desmond Tutu HIV Centre runs the community ARV clinics in Gugulethu and Masiphumelele. Since 1993, Prof. Wood supervised the first dedicated HIV clinic in the Western Cape at Somerset Hospital and he has extensive experience in administering ARVs. He has published widely on HIV management, ARV adherence and TB interaction with HIV. Prof. Wood also serves as TAC's medical advisor.

Academics/Clinicians

Dr. Gary Maartens: Clinical pharmacologist, founder of the adult HIV clinic at Groote Schuur Hospital and lecturer at the University of Cape Town. Dr. Maartens is the Head of the Division of Pharmacology and the former Head of the Infectious Diseases Unit at the hospital and is widely regarded as the country's leading HIV clinician. He also serves on national and local health policy committees. Dr. Maartens assisted in the formulation of the *National Antiretroviral Treatment Guidelines* and is an editorial board member of *Lancet Infectious Diseases*, the *Southern African Journal of Epidemiology and Infection* and the *Southern African Journal of HIV Medicine*.

Dr. Andrew Boulle: Researcher at the Infectious Diseases and Epidemiology Unit, University of Cape Town. Dr. Boulle has been instrumentally involved in the MSF and Provincial Department of Health ART sites in Khayelitsha since their inception. He has also published widely on the provision of ART through the public sector and is the author of the *CT ARV Costing Model* that has been generically adapted and approved by WHO. In addition, Dr. Boulle has developed an HIV clinical information system model that is being used by the Provincial Department of Health in monitoring and evaluating ART implementation.

Civil Society Partners and ARV Roll-Out Monitoring Organisations

Ms. Siphon Mthathi: General Secretary of the Treatment Action Campaign (TAC). Ms. Mthathi was elected to this position at the Third TAC National Congress in 2005 having been a TAC member since 2000. She played an instrumental role in setting up TAC's branches in the Western Cape and also led the design and implementation of TAC's Treatment Literacy Programme, which has been recognized by UNAIDS as a best practice. As General Secretary, Ms. Mthathi oversees TAC's day-to-day functioning.

Ms. Fredalene Booysen: Provincial Organizer of the Western Cape Treatment Action Campaign (TAC) Provincial Office. Ms. Booysen liaises with all TAC Western Cape branch and district offices, organizing TAC activities and coordinating with key stakeholders to address challenges in ART implementation at the community level.

Ms. Ntombozuko Khwaza: Treatment Project Co-ordinator of the Western Cape Treatment Action Campaign (TAC) Provincial Office. Ms. Khwaza coordinates TAC's own treatment provision within the province -- working to identify needs and gaps in coverage from the public sector ART programme.

Ms. Fatima Hassan: Attorney and former Deputy Head of the AIDS Law Project (ALP) and secretariat of the Joint Civil Society Monitoring Forum (JCSMF). Ms. Hassan works in the Law and Treatment Access Unit of the ALP in Cape Town. She has extensive expertise in public interest litigation, education, training and legal reform in the area of HIV/AIDS and discrimination, and was appointed by the Minister of Health as a member of the Council for Medical Schemes. In her role at ALP, she monitors the implementation of the national Operational Plan.

Potential Constraints and Biases of the Dissertation

It is imperative to chronicle factors that may have biased this dissertation. While there were no significant constraints in accessing key stakeholders and relevant information, it is important to note that particular emphasis has been placed on ART sites which had the greatest accessibility and published literature. These include government ART sites being supported by MSF in Khayelitsha, ARK and the Desmond Tutu HIV Centre in Gugulethu and Masiphumelele. As such, this study could be considered biased in its geographical representation of the roll-out of the ART programme in the Western Cape.

In addition, an interview with Dr. David Coetzee, Director of the Infectious Disease and Epidemiology Unit and lecturer at the University of Cape Town, was desired but, unfortunately, due to his heavy work load he was unable to avail himself for a meeting.

Furthermore, since this research is being conducted at the meso level, it is potentially further constrained by the lack of perceptions and experiences at the patient level, and this would be an important further topic of study.

It is important to also note how the researcher's own identities may have influenced this study. For one, the researcher is a foreigner (Lebanese-American). While this did not affect access to key stakeholders to interview, and there were no language barriers encountered precluding the successful completion of interviews, it could have influenced the lenses by which the data was analyzed. Conversely, being a foreigner may have provided this study with additional insights that would not have been obviously apparent otherwise. Bernard (1994) notes that the advantages of a researcher being an outsider is that he/she notices socio-cultural patterns that insiders often take for granted. In addition, the researcher is currently employed by the United Nations Development Programme's HIV/AIDS Group at its headquarters in New York and has many connections to the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). This could have resulted in the research having a subjectively biased view. Moreover, the interviewees were made aware of the background of the researcher and, as such, could have adjusted their statements in the interviews -- particularly when considering persisting challenges -- in an effort for the programme to appear more favourable.

Finally, a possible and significant constraint in this work stems from the diverse range of levels of wealth between provinces in South Africa as a result of the legacy of apartheid -- with the Western Cape being one of the richest of the nine provinces (Cummins, 2002). Literature has shown that the level of wealth is a key determinant in the spread of the HIV/AIDS epidemic (Barnett & Whiteside, 2002). It has also been suggested that this determines the corresponding aggressiveness and efficacy of national HIV/AIDS responses. As a bare minimum, because government in richer countries/provinces/districts have greater access to financial and other resources, and tend to have 'stronger' governance structures and systems, responses to public health threats such as HIV/AIDS tend to be swifter and more expansive (Gauri & Lieberman, 2004). Moreover, cross-national statistical analyses have shown that GDP per capita is correlated with higher levels of per capita government spending on HIV/AIDS, even after controlling for variances in estimated levels of HIV prevalence (Lieberman, 2004 quoted by Gauri & Lieberman, 2004). Hence, since the relative wealth of the Western Cape Province cannot be controlled for with comparison to other provinces, this factor may in fact 'over-ride' another province's ability to benefit from some of the lessons learnt and gleaned in this work.

CHAPTER 3:
Scaling Up of Antiretroviral Therapy in the Western Cape:
Key Factors that are Contributing to the Programme's Success

Within the national milieu of government resistance to providing ARVs, in 1999 the Provincial Government of the Western Cape Department of Health (PGWC) forged ahead with implementation of PMTCT and a pilot ART project in 2001 -- long before the national Operational Plan was launched. Due to the subsequent adoption of this treatment plan (with accompanying human and financial resources for provinces), substantial donor funding in the Western Cape (particularly R430 million over five years from the GFATM (Thom, 2004)¹⁷), and drastic reductions in ARV prices, the Western Cape was able to roll-out a treatment programme throughout the province in the course of 2004 and 2005 (Abdool Karim, 2004; Abdullah, 2005b)¹⁸. Many partners believe it was "well placed to do well" given the province's demonstrated political will early on to provide this service through the public sector, as well as its prior experience in administering HIV/AIDS drugs¹⁹. By June 2006, 44 ART sites had been accredited and were providing therapies to adults and children with the aim to expand this to 50 sites by April 2007 (PGWC & UCT, 2006). Furthermore, as *Figure 13* overleaf illustrates, by the end of June 2006, more than 20,000 people were receiving ART treatment. (See *Appendix B* for a full list of the current operating sites in the Western Cape as well as patients on ART in June 2006).

¹⁷ Two-thirds of this GFATM grant is allocated to the provision of treatment and this greatly jump-started the province's ability to rapidly scale-up ART (Cloete, 2006, personal comm., 8 August; Naimak, 2006).

¹⁸ Cloete, 2006, personal comm., 8 August.

¹⁹ Boule, 2006, personal comm., 27 July; Goemaere, 2006, personal comm., 18 July; Hassan, 2006, personal comm., 11 July; Maartens, 2006, personal comm., 29 June.

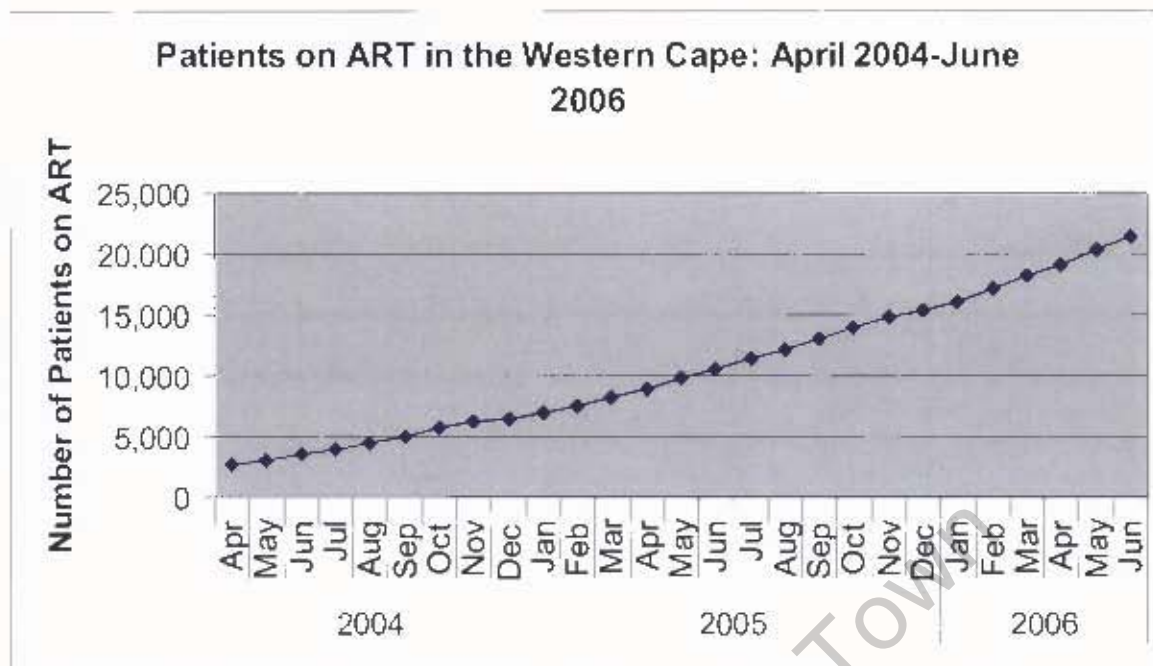


Figure 13 : PATIENTS ON ART IN THE WESTERN CAPE, APRIL 2004 – JUNE 2006 (SLINGERS, PROVINCIAL GOVERNMENT OF THE WESTERN CAPE, 2006).

In the absence of a national monitoring and evaluation system (IIPC, 2006), the PGWC, in partnership with the University of Cape Town (UCT), has effectively developed its own -- resulting in the Western Cape being one of the only provinces in South Africa with adequate data to offer tangible outcomes from ART delivery²⁰. As noted already in *Figure 10*, the province has rolled out ART swiftly, exceeding the Operational Plan targets for 2004 and 2005. With 72% of the Western Cape provincial population using the public sector health system (Abdullah, 2005a), this speedy ART programme expansion offers much hope to PLWHA in the province. By December 2005, it was estimated that 55.7% of people that need ART in the Western Cape had access to it (Nattrass, 2006a) -- compared to a national average of 10% (Abdullah, 2006 quoted by Herman, 2006).

Following I will discuss the key factors that are contributing to the success of the ART scale-up in the Western Cape. It is important to note that nearly all informants had consensus on these themes as aspects that have facilitated the programme's effective performance.

²⁰ Boule, 2006, personal comm., 27 July; Grimwood, 2006, personal comm., 10 July; Oster, 2006, personal comm., 30 June.

Epidemiology of HIV and Historically Strong Health Systems in the Western Cape

Literature has established that persons who are economically disadvantaged have greater susceptibility to HIV infection (Fenton, 2004; Head, 1992; Kalichman *et al.*, 2005; McCoy, 2003; Stillwaggon, 2002 & 2003). The Western Cape, consisting of 10.1% of the South African population, has the highest level of per capita income, employment and literacy in South Africa as evidenced by the Human Development Index (Abdullah, 2005b; Statistics South Africa, 2003). Given the higher socio-economic status of the Western Cape population, the HIV prevalence is lower than any other province and is almost half the national average (30.2%) at 15.7% (DOH, 2006a) (see *Figure 14* below for a comparison of HIV prevalence rates by provinces among antenatal clinic attendees²¹, 2003-2005). Nevertheless, the epidemic has continued to increase over the last ten years from a prevalence rate of 1.2% in 1994 to 15.7% in 2005, and it is expected to continue in this upward trend over the next five years (Abdullah, 2005b; DOH, 2006a; PGWC, 2005). HIV/AIDS accounts for the largest burden of disease in the province and is the largest cause of mortality among children and women aged 15-29 (Abdullah, 2005b:248). As such, public health officials view it as the "single largest health crisis facing the Western Cape at the present time" (*ibid*).

PROVINCE	HIV pos. 95% CI 2003	HIV pos. 95% CI 2004	HIV pos. 95% CI 2005
KwaZulu-Natal	37.5 (35.2 - 39.8)	40.7 (38.8 - 42.7)	39.1 (36.8 - 41.4)
Mpumalanga	32.6 (28.5 - 36.6)	30.8 (27.4 - 34.2)	34.8 (31.0 - 38.5)
Gauteng	29.6 (27.8 - 31.5)	33.1 (31.0 - 35.3)	32.4 (30.6 - 34.3)
North West	29.9 (26.8 - 33.1)	26.7 (23.9 - 29.6)	31.8 (28.4 - 35.2)
Free State	30.1 (26.9 - 33.3)	29.5 (26.1 - 32.9)	30.3 (26.9 - 33.6)
Eastern Cape	27.1 (24.6 - 29.7)	28.0 (25.0 - 31.0)	29.5 (26.4 - 32.5)
Limpopo	17.5 (14.9 - 20.0)	19.3 (16.8 - 21.9)	21.5 (18.5 - 24.6)
Northern Cape	16.7 (11.9 - 21.5)	17.6 (13.0 - 22.2)	18.5 (14.6 - 22.4)
Western Cape	13.1 (8.5 - 17.7)	15.4 (12.5 - 18.2)	15.7 (11.3 - 20.1)
National	27.9 (26.8 - 28.9)	29.5 (28.5 - 30.5)	30.2 (29.1 - 31.2)

Figure 14 : PROVINCIAL HIV PREVALENCE ESTIMATES: ANTENATAL CLINIC ATTENDEES, SOUTH AFRICA, 2003-2005. (DEPARTMENT OF HEALTH, 2006A).

²¹ Academics question HIV prevalence rates that are extrapolated from antenatal clinic surveys that only target women who have unprotected sex, since they are pregnant, as well as women of low socio-economic status who are using public health services as they can't afford private health care. That is, the data does not adequately represent all populations groups in South Africa (Bourne, 2005). Nevertheless, I am using these surveys as a baseline for comparison between the different provinces.

While the Western Cape remains one of the richest of the nine provinces with, for example, the highest public spending on health, there are extreme disparities between rich and poor and great inequalities in health outcomes along socio-economic lines (Abdullah, 2005b; Castro-Leal, 1999; Cummins, 2002). For example, HIV antenatal prevalence rates vary in the province from as high as 33% in Khayelitsha to as low as 1.2% in Blaauwberg (PGWC, 2005). Moreover, antenatal surveys have shown that there have been greater increases in HIV prevalence in urban areas as compared to rural areas, the former of which constitute approximately 70% of the provincial population (PGWC, 2002, 2003, 2004 & 2005). (See *Figure 16* on page 35 for maps indicating varying HIV prevalence rates in the Western Cape Province).

As a result of the Cape having stronger health systems due to the legacy of apartheid that prioritized service provision in Afrikaner stronghold cities and towns (Coulson *et al.*, 1998), the PGWC has been able to speedily target high prevalence urban areas through the establishment of ART sites within existing health infrastructures. This already well-functioning, mainly urban-based provincial health system includes three tertiary hospitals, 36 district and regional hospitals, 64 community health centres, 252 clinics, 131 mobile clinics as well as the highest rates of doctors (72.4) per 100, 000 population and hospital beds (over 8,000) in South Africa (Abdullah, 2005b). Health provision in the rural areas of the province, however, still remains severely constrained. While people are reached by the mobile clinics they have to travel enormous distances to the nearest town for sophisticated health interventions such as HIV/AIDS treatment (Abdullah, 2005b; Cummins, 2002). Thus, the epidemic's spatial progression in the province, concentrated largely in urban settings, is facilitating a more effective and swift response.

A similar trend is now seen in Gauteng (TAC, 2005b) which also has a chiefly urban epidemic and, like the Western Cape, a history of the highest spending in public health (Benatar, 2004; Castro-Leal, 1999). This is not the case in other provinces. For instance, KwaZulu-Natal, which is home to 21% of South Africa's population, has predominantly rural populations (Statistics South Africa, 2003), which, compounded with a history of being disproportionately neglected during the apartheid era²², makes the challenges of ART provision much greater.

²² The entire health budget for KwaZulu-Natal in 1982 was equivalent to the budget of the Johannesburg Hospital (Baldwin-Ragaven *et al.*, 1999).

In addition, ten-year trends of the Western Cape HIV epidemic compared to the national epidemic suggest that the provincial epidemic is in an earlier phase (PGWC, 2003) (See *Figure 15* below). Thus, the province has a window of opportunity to stabilize the epidemic through targeted prevention and treatment efforts (PGWC, 2003, 2004 & 2005). While the overall effects of scaled-up interventions like the PMTCT and the ART on the epidemic's trajectory are still to be seen, the Western Cape, unlike other provinces with mature epidemics, is well-positioned to see a positive shift in coming years²³.

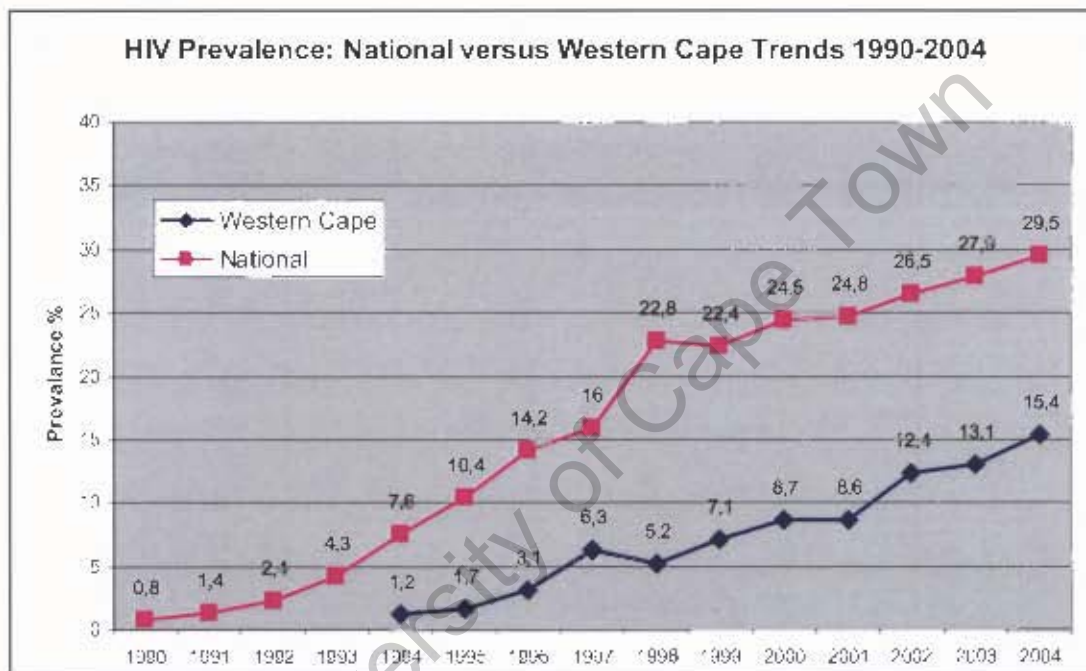
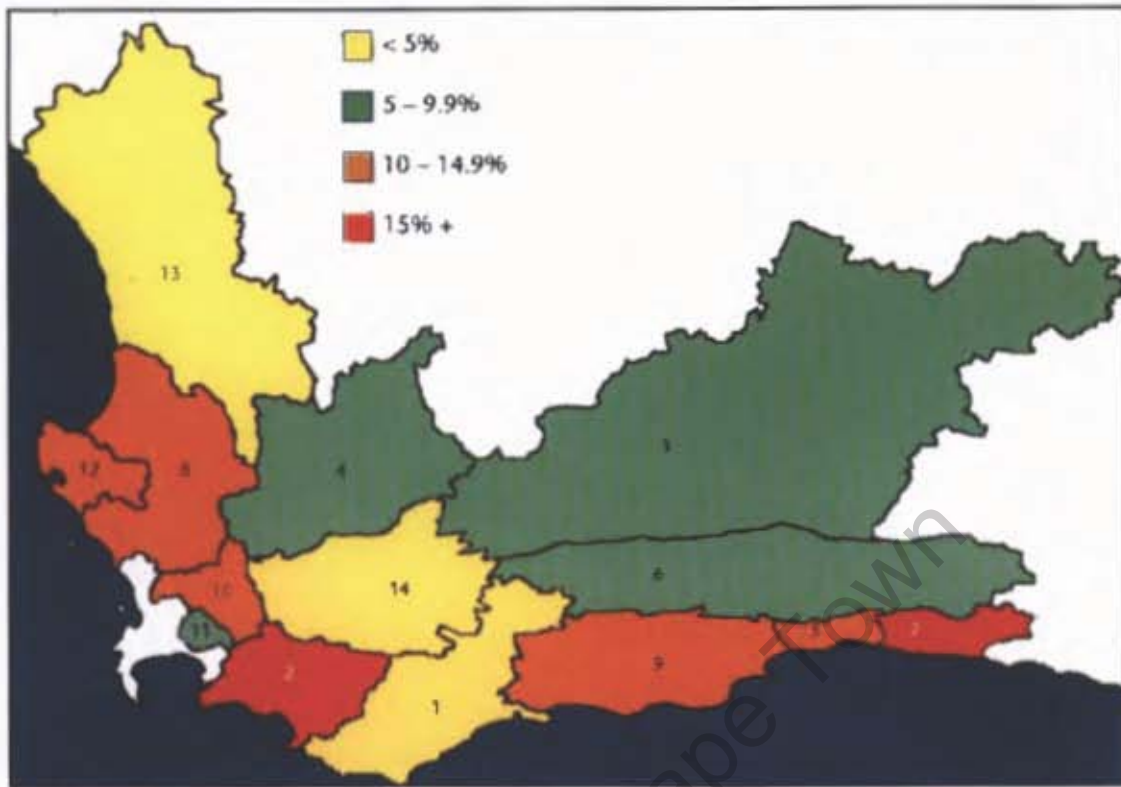
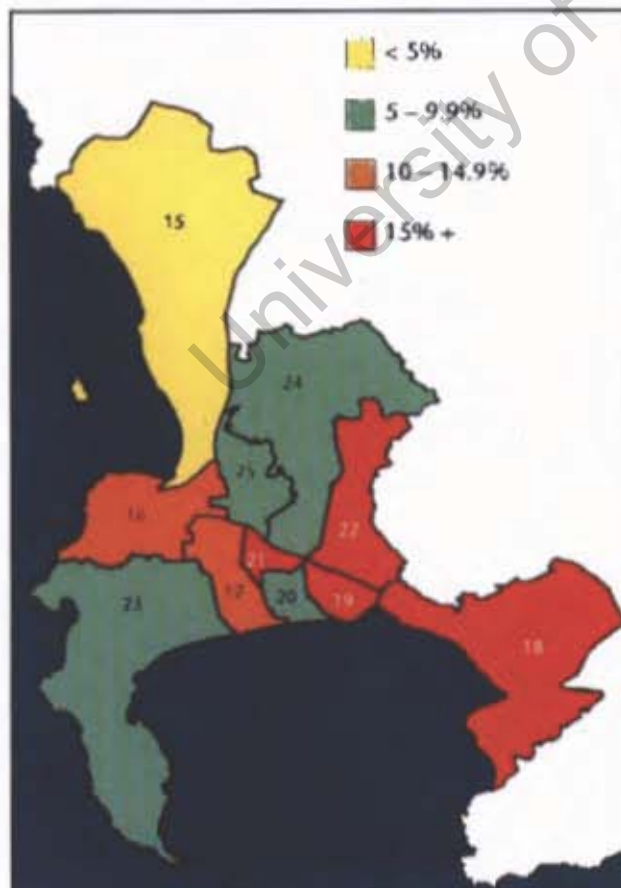


Figure 15 : COMPARISON OF TRENDS OF ANTENATAL CLINIC HIV PREVALENCE RATES NATIONALLY AND IN THE WESTERN CAPE, 1990-2004. (ADAPTED FROM WESTERN CAPE DEPARTMENT OF HEALTH, 2005 AND DEPARTMENT OF HEALTH, 2005).

²³ These projections of the epidemic, with or without prevention and treatment efforts, have been extrapolated by the ASSA 2000 Interventions Model (Nattrass, 2004).



8.2. HIV Prevalence: Metropole Districts 2003



1. Bredasdorp/Swelendam
2. Caledon/Hermanus
3. Central Karoo
4. Ceres/Tulbach
5. George
6. Klein Karoo
7. Knysna/Plettenberg Bay
8. Malmesbury
9. Mosselbay/Langeberg
10. Paarl
11. Stellenbosch
12. Vredenberg
13. Vredendal
14. Worcester/Robertson

15. Blaauberg
16. Cape Town Central
17. Greater Athlone
18. Helderberg
19. Khayelitsha
20. Mitchell's Plain
21. Nyanga/Gugulethu
22. Oosterberg
23. South Peninsula
24. Tygerberg Eastern
25. Tygerberg Western

Figure 16 : MAPS INDICATING VARYING HIV PREVALENCE RATES IN THE WESTERN CAPE PROVINCE, 2003. (WESTERN CAPE DEPARTMENT OF HEALTH, 2004).

Building Upon the Prevention of Mother-To-Child (PMTCT) Transmission Programme and Pilot ARV Sites

The Western Cape PMTCT initiative served as the frontrunner for the provision of ARV triple combination therapy for long-term treatment of adults and children. Most informants greatly stressed the importance of this programme in informing the provision of ART. Dr. Maartens, a leading HIV/AIDS clinician of Groote Schuur hospital, aptly encapsulated this overall sentiment by citing it as the “*cornerstone* to the success [of the ART programme]”²⁴.

This project was initiated in 1999 in the township of Khayelitsha that has approximately 500,000 inhabitants (Kasper *et al.*, 2003) and current antenatal HIV prevalence rates as high as 33% (PGWC, 2005). Khayelitsha is considered to be an extremely impoverished area with 50% of its population unemployed and 70% living in shacks (Kasper *et al.*, 2003). The government first offered PMTCT in two maternal wards providing VCT and ARVs to prevent mother-to-child transmission of HIV during pregnancy and labour (Abdullah, 2005b)²⁵. In addition, follow-up care was also instituted at nine clinics in the area to provide safety guidance on formula feeding or breastfeeding as well as infant HIV testing at nine and 18 months (Abdullah, 2005a). Since 1999, this pilot PMTCT programme in Khayelitsha has expanded to become one of the continent’s biggest with over 30,000 women having accepted to be counselled and tested in five years (Abdullah, 2005a; Coetzee *et al.*, 2005). Moreover, as a result of this intervention, mother-to-child transmission rates have remarkably decreased from 30% (Nattrass, 2004:70) to 5.5% in 2004 (Abdullah, 2005a). Furthermore, this PMTCT model has now been replicated in 300 antenatal and child health clinics across the province including the majority of mobiles (Abdullah, 2005b). Almost 100% of eligible patients in the Western Cape now have access to drugs to prevent this vertical transmission of HIV (Benatar, 2004). It is also expected that similar reductions in transmission rates will be seen throughout the province in 2006 (Abdullah, 2005b).

²⁴ Maartens, 2006, personal comm., 29 June.

²⁵ Goemaere, 2006, personal comm., 18 July.

Building upon this programme, a pilot ART project was launched in May 2001 in Khayelitsha. In partnership with Médecins Sans Frontières (MSF), an international NGO, the PGWC offered free triple-combination ARVs in three dedicated sites within community health services that had already been providing HIV prophylaxis and treatment of opportunistic infections: Site B Khayelitsha, Site C Nolungile and Michael Mapongwana (Coetzee *et al.*, 2004a; Kasper *et al.*, 2003)²⁶. Mothers and babies who tested positive through the PMTCT programme were targeted for ART, and this service was also extended to the broader community (Kasper *et al.*, 2003)²⁷. This pilot demonstrated positive health outcomes with 86.3% of ARV patients remaining alive after 24 months of treatment -- exceeding survival rates even evidenced in similar interventions in Canada and the USA (Coetzee *et al.*, 2004a; MSF & UCT, 2003). Moreover, no deaths were attributed to adverse reactions to these therapies (Coetzee *et al.*, 2004a; Kasper *et al.*, 2003). As a result of the success in Khayelitsha, by December 2003, nine sites in the Western Cape were piloting ARV provision (Abdullah, 2005b). The three Khayelitsha sites, however, remained the cornerstone of the provincial ART programme: By June 2006, almost 4,500 patients were on ARVs in this township -- about a quarter of the total number of people on ART in the Western Cape (PGWC, 2006).

This pilot project represented one of the first attempts to integrate ART as part of a comprehensive government response to HIV/AIDS in a health district and was hailed by implementers as proof that the use of ART at primary health care level in a resource-poor setting was safe, feasible and replicable (Coetzee *et al.*, 2004a; Kasper *et al.*, 2003; MSF & UCT, 2003; WHO, 2003)²⁸. Dr. Cloete²⁹ of the PGWC reflects that this formed the impetus for further expansion of ART in the province noting that:

“We had piloted the thing since 2001, and we built up collective experience of how to do a treatment programme, and a lot to do with that is the experience we built up specifically in primary care in Khayelitsha with the MSF site.”

²⁶ Goemaere, 2006, personal comm., 18 July.

²⁷ Goemaere, 2006, personal comm., 18 July.

²⁸ Cloete, 2006, personal comm., 8 August; Goemaere, 2006, personal comm., 18 July; Naidoo, 2006, personal comm., 7 August.

²⁹ Cloete, 2006, personal comm., 8 August.

Moreover, some believe that this success sent a strong signal to other provinces and national government that had been claiming that provision of such a service was unattainable in a context like South Africa. It is important to note, however, that these projects -- while implemented in a resource-constrained environment -- were actually resource-intensive during the pilot phase with ample donor funds and human resources. Many at the time called into question the feasibility of large-scale replication of such a resource-rich model.

Nevertheless, the highly successful PMTCT programme and pilot ART sites offered many valuable lessons and insights from which to expand ART provision. *Firstly*, they allowed the provincial government to establish expertise in the procurement and management of the supply chain of ARVs as well as in their administration (Abdullah, 2005b). More specifically, the PMTCT programme in Khayelitsha illustrated that complex regimens could be delivered effectively on a large scale within primary health care services (Coetzee *et al.*, 2005). *Secondly*, these projects permitted for training and building of skills at the clinic level in effective ways to deliver ART services (Abdullah, 2005b; Kasper *et al.*, 2003). *Finally*, the pilot ART project demonstrated that because patients on ARVs can experience rapid improvements in their health, follow-up could be done by nurses instead of doctors (Kasper *et al.*, 2003). In turn, these positive health outcomes in patients were also shown to greatly boost health care practitioners' morale (Kasper *et al.*, 2003)³⁰. Thus, the introduction of ART could potentially be seen as an *opportunity* to begin to address fundamental problems within the health care system such as provider attitudes (Schneider & Coetzee, 2003). With this wealth of experience in ARV provision, the Western Cape was well-placed to extend this service to other sites when the national government announced the Operational Plan.

While the Western Cape had a head-start compared to other provinces, there has been much learning that can be extrapolated to other provincial settings. In particular, established protocols, assessment tools, guidelines and training materials for health care providers and counsellors can be adapted for other provinces in the absence of national directives in certain areas. Lessons concerning management of case loads and how responsibilities can be delineated between doctors and nurses as well as strategies to address human resources shortages and fatigue are also important.

³⁰ Wood, 2006, personal comm., 7 August.

Building Effective and Successful Partnerships

One of the most pertinent lessons from the PMTCT programme and pilot ART project has been the importance of involving partners in implementation. For phasing in the ART expansion, the Western Cape provincial government outsourced the entire counselling component to NGOs (though this would be provided on-site), established strong links with TAC to ensure community involvement and treatment literacy³¹ at most of the metro-based services, and cultivated partnerships with other NGOs, local authorities and clinicians from academic hospitals and universities (Abdullah, 2005b). Building upon the MSF example, ART sites were also established in partnership with the Desmond Tutu HIV Centre (in Gugulethu and Masiphumelele) and Kidzpositive (at Groote Schuur Hospital) (Abdullah, 2005b)³². Other operational research projects were also pursued hand-in-hand with NGOs and university hospitals to determine best practices in the provision of ARVs in the public sector (Abdullah, 2005b)³³.

These partnerships and their associated funding were critical in the pilot phase when there was still no national policy for the provision of ART through the public sector (Naimak, 2006; Natrass, 2006a). Dr. Maartens³⁴ of Groote Schuur hospital notes that:

“The key to our success was in a sense political in that there was enormous reluctance on the part of the state to start PMTCT and ART. The way that the local government got around the national government’s reluctance to do this was to set up pilot sites [with partners], to pretend, in a sense, that it was research or a study. It wasn’t entirely a pretence because if you are going to start a new intervention it is a good idea to start it at a centre. National government were supportive of [these partnerships].”

³¹ TAC (2003) defines their treatment literacy programmes as including discussions on safer sex, nutrition, mother-to-child transmission prevention, post-exposure prophylaxis, treatment of opportunistic infections, accessing social grants, conditions in the public health service and antiretroviral therapy.

³² Cloete, 2006, personal comm., 8 August.

³³ Cloete, 2006, personal comm., 8 August.

³⁴ Maartens, 2006, personal comm., 29 June.

Further, Dr. Goemaere³⁵ of MSF comments that:

“[The first ARV project with MSF] was called private research in a public facility to see if it works. It was a crazy kind of thing. When you put things under operational research you are basically allowed to do what you want as long as it is an ethical approach – which we had.”

As such, these organisations enabled the pilot process to proceed when the PGWC could not ‘advertise’ such a programme nationally and also allowed for important research to be conducted on how to implement ART programmes at the primary care level. Moreover, Dr. Boulle of UCT observes that these services, although partly or fully run by partners still, are seen as government programmes -- allowing for the continuation of vital research outputs while actually providing life-saving health services to communities³⁶.

A particularly noteworthy partnership has been with an NGO called Absolute Return for Kids (ARK). This collaboration aims at speeding up accreditation of new ART sites to expand access in more areas. ARK instantly upgrades the potential site’s capacities by supplying medical experts in ART on a short-term basis with the view that the PGWC will secure appropriate permanent staff within a few years as well as improve the site’s overall health systems (Abdullah, 2005b). Dr. Grimwood³⁷ of ARK notes that:

“[ARK] pays for staffing costs, [and] works longer in this area [of human resources], because the province could not get the staff we could, and [we] move our staff around [different sites] in the SWAT team approach...[ARK] trains staff [and recruits them] locally from the private sector, we’ve taken people out of retirement. We pay the same rates, the same level that government is paying....so then the issue of the province taking over and sustainability is not put at risk...when we exit. We have encouraged our staff to apply for government positions, which has happened and has been successful.”

³⁵ Goemaere, 2006, personal comm., 18 July.

³⁶ Boulle, 2006, personal comm., 27 July.

³⁷ Grimwood, 2006, personal comm., 10 July.

Significantly, this approach, thus, ensures that human resources are strengthened and that no existing DOH employees are removed from their present positions since recruitment takes place from the private sector and retired personnel. Moreover, by using contracts that are on par to government, the ultimate retention of trained and skilled staff within the PGWC is ensured -- unlike most donor-funded programmes that offer higher salary scales. To date, ARK has provided this kind of technical assistance to 22 ART sites in the Western Cape³⁸ -- half of all existing sites that are currently providing ARVs in the province.

This is a model that would be highly recommended for other provinces. Given the shortage of human resources in the public health system (ITPC, 2006; Kober & Van Damme, 2004; McCoy *et al.*, 2005; Schneider & Coetzee, 2003; TAC, 2005a, 2005c & 2006b), and more particularly, experts in ART (TAC & ALP, 2004 & 2005), the need to share expertise in ARV provision across the provinces is essential if South Africa is to successfully roll-out a national HIV/AIDS treatment programme. Moreover, rapidly addressing human resource shortages is considered one of the key challenges in scaling-up HIV/AIDS treatment (Institute of Medicine, 2004; Kovsted, 2005) and this model offers an innovative solution. With the expansion of its work to other provinces, namely the Eastern Cape, KwaZulu-Natal and Mpumalanga, ARK is now using the Western Cape sites as ‘training grounds’ for other recently recruited ART personnel from across South Africa³⁹.

In addition, the Western Cape holds regular public briefings on the rollout of ART to ensure widespread stakeholder involvement (TAC & ALP, 2004)⁴⁰. This participation of civil society has created an environment of “openness and unity” -- lending credibility to the PGWC and its political willingness to expand access to ART (Naimak, 2006:19). While there are certainly tensions within the PGWC’s partnerships, most partners perceive the programme as inclusive. Importantly, informants all noted that this is one of the key factors that have facilitated the speedy expansion of the programme -- allowing the PGWC to capitalize on the cumulative knowledge and expertise of all implementing and research partners. In addition, this team effort approach to implementation has enabled the province to attract good quality staff and generate greater resources (Abdullah, 2005b:258)⁴¹.

³⁸ Grimwood, 2006, personal comm., 10 July.

³⁹ Grimwood, 2006, personal comm., 10 July.

⁴⁰ Slingers, 2006, personal comm., 9 August.

⁴¹ Slingers, 2006, personal comm., 9 August.

Finally, in an effort to ensure a programme that is sustainable, the PGWC regularly holds discussions with partners concerning the takeover of operations by the provincial government within realistic time-frames (usually three to five years)⁴². This is a critical strategy in the province that has allowed for the immediate scaling-up of treatment provision while the provincial government strengthens health systems and builds a pool of trained human resource expertise in this area. For example, while the three sites in Khayelitsha were initially fully run by MSF, the PGWC began to take this over in 2005, in particular the supply of the ARVs and the recruitment of doctors and nurses (TAC, 2006a)⁴³. Full responsibility of the ART programme in Khayelitsha will be assumed by government by 2008⁴⁴. In addition, after three years, ARK is now in the process of exiting from the 22 ART sites in the Western Cape where it has provided medical experts and systems strengthening, and the provincial government is taking on these functions and some of the staff⁴⁵. Such strategies would greatly assist other provinces in jump-starting their scale-up campaigns (TAC & ALP, 2005).

Strategies that are Ensuring High Rates of Adherence

Adherence to ART is well-recognized to be a critical component of individual and programmatic treatment success (WHO, 2004a). If patients do not successfully take their medications, not only will they have negative health outcomes but they are likely to develop a drug-resistant strain of HIV (*ibid*). In such a scenario, if an individual chooses to attempt treatment again and fails to respond to the existing options in first-line and second-line regimens⁴⁶, they would have exhausted all treatment possibilities (*ibid*). From a programmatic perspective, second-line drugs are still largely unaffordable for governments (MSF, 2005). If large numbers of patients stop and start their ART, and, thereby, develop drug resistant strains requiring second line treatments, the ART projects may no longer be affordable and sustainable. Furthermore, patients who develop drug resistance are at risk of spreading the resistant virus, thus threatening the treatment potential of new patients entering the programme (Abdullah, 2005b). Lack of adherence to life-long HIV/AIDS drug therapies, and the subsequent widespread development of community-acquired resistance⁴⁷ -- also

⁴² Cloete, 2006, personal comm., 8 August.

⁴³ Goemaere, 2006, personal comm., 18 July.

⁴⁴ Cloete, 2006, personal comm., 8 August; Goemaere, 2006, personal comm., 18 July.

⁴⁵ Cloete, 2006, personal comm., 8 August; Grimwood, 2006, personal comm., 10 July.

⁴⁶ First line regimens are followed and in the case of adverse side effects or acquired immunity, second line regimens are pursued (Kovsted, 2005; WHO, 2004a).

⁴⁷ Drug resistance surveillance and monitoring initiatives need to be an essential part of any ART

known as the feared “tsunami of resistance”⁴⁸ -- place the public health benefits of a treatment programme at great risk.

Studies of the ART sites in the Western Cape have shown that adherence is not a barrier to successful ART in South Africa (Bekker *et al.*, 2006; Coetzee *et al.*, 2004a; Kasper *et al.*, 2003; Orrell *et al.*, 2003; WHO; 2003)⁴⁹. This has been evidenced by the proportion of individuals on treatment who are achieving viral suppression and matches results seen in North America and Europe (Bekker *et al.*, 2006; Orrell *et al.*, 2003). Moreover, it has been found that socio-economic status as well as sex and HIV stage does not predict adherence (Orrell *et al.*, 2003)⁵⁰. This is an extremely critical finding given some concerns that have been articulated internationally that poor Africans cannot adhere to ARV treatment (Kovsted, 2005; Orrell *et al.*, 2003)⁵¹. In addition, a recent research study in Gugulethu demonstrated that rapid scale-up of ART within an urban South African setting did not have adverse effects on programmatic outcomes (Bekker *et al.*, 2006). Thus, the Western Cape public sector ART programme is in the forefront of demystifying global perceptions about delivery of ART and adherence to medications in resource-constrained contexts. Projects in Brazil, Haiti, Uganda and Senegal are also contributing to this growing body of work (Coetzee *et al.*, 2004a; Egger *et al.*, 2005; Farmer *et al.*, 2001; Orrell *et al.*, 2003).

To ensure high adherence and retention in care rates, the PGWC is implementing several community-based psycho-social support models. While research on best practices in this area is still on-going (Abdullah, 2005b), they are all based on a patient-centred education approach combined with community involvement and/or facility-based support (Pienaar *et al.*, 2006). Central to these models is the understanding that stigma associated with HIV/AIDS may discourage people from getting tested, starting ART and continuing treatment (Stewart *et al.*, 2004), and that government and community leaders should create a

programme (WHO, 2004a). In the USA and Europe, approximately 10% of new HIV infections involve viral strains that are resistant to at least one drug (*ibid*).

⁴⁸ Mthathi, 2006, personal comm., 17 July.

⁴⁹ Grimwood, 2006, personal comm., 10 July; Maartens, 2006, personal comm., 29 June; Wood, 2006, personal comm., 7 August.

⁵⁰ Three times daily therapy was the strongest predictor for poor adherence (Orrell *et al.*, 2003). This result is found in other countries as well and is the impetus for pushing pharmaceuticals to produce triple combination (Fixed Dose Combination) HIV/AIDS drugs that need to only be taken twice a day (MSF, 2004; WHO, 2004a).

⁵¹ Jones (2004) outright dismisses this notion as a reflection of a prejudicial general perception that Africans are unsophisticated and backward.

culture of openness and support to counteract this (Institute of Medicine, 2004; WHO, 2004a). In Khayelitsha, this has involved the selection of a treatment coach who becomes the main individual in psycho-social support, backed by site-based counsellors and regular support groups (Coetzee *et al.*, 2004a)⁵². In Gugulethu, lay counsellors are community-based, doing home visits and unannounced pill counts, as well as working with clinic staff in patient management for as many as 30 patients (Abdullah, 2005b; Bekker *et al.*, 2006). At the Tygerberg Hospital, patients are counselled by site-based counsellors and referred to home-based care organisations for psycho-social support in the community (Abdullah, 2005b). This latter example represents an innovative way of utilizing capacity in this existing sector, particularly as the need for home-based care decreases as more patients are on ART. ARK has developed a Patient Advocate model that involves psycho-social support from both the patient advocate (a nominated community member) as well as a 'treatment buddy' (a friend or relative), and includes a system of home visits, an array of adherence tools such as the 'pill box' and is backed by on-site counsellors and support groups⁵³. The Patient Advocate manages 20 patients in the first six months (the "TLC" high maintenance period at the on-set of therapy) and, once treatment adherence has stabilized, expands this to 70 patients. In all these cases, TAC plays a central role mobilizing the community and conducting treatment literacy campaigns for patients as well as the broader public (Abdullah, 2005b; Coetzee *et al.*, 2004a; TAC, 2003, 2004 & 2005a).

The particular role of TAC in ensuring high adherence rates at ART sites in the Western Cape metro areas deserves special attention. Treatment literacy has shown to be a powerful tool to community mobilization because it not only offers education on health care, HIV and HIV/AIDS medicines, but also on human rights, the politics of treatment access and activism (TAC, 2005a; WHO, 2003). In communities where HIV/AIDS stigma is widespread, this knowledge can be transformative, enormously increasing confidence and often overall well-being as well (TAC, 2005a; WHO, 2003). At the cornerstone of this activity is that education and awareness is targeted at both potential ART patients within the health care setting as well as the surrounding community at large⁵⁴. Moreover, research indicates that where TAC grassroots activities are most concentrated, ART and PMTCT uptake is high (Robins, 2004; TAC & ALP, 2004). This would suggest that TAC's health

⁵² Goemaere, 2006, personal comm., 18 July.

⁵³ Grimwood, 2006, personal comm., 10 July; Jason, 2006, personal comm., 10 July.

⁵⁴ Khwaza, 2006, personal comm., 20 July; Mthathi, 2006, personal comm., 17 July.

activism is contributing to countering socio-cultural barriers to access to treatment including HIV/AIDS fear and stigma. For example, a study of nine commuter sites across South Africa, including Khayelitsha, found that Khayelitsha residents had the highest levels of HIV testing, desire to be tested, condom use and willingness to join an AIDS club (Parker *et al.*, 2002). While this is certainly attributable to the provincial government's comprehensive approach to HIV/AIDS care in this township, the significant role of TAC in Khayelitsha is well-documented and widely acknowledged (Kasper *et al.*, 2003; MSF & UCT, 2003; Robins, 2004; WHO, 2003)⁵⁵. Robins (2004:666) argues that TAC's successful grassroots mobilization has introduced "new concepts of health citizenship" in South Africa within the politics of class and access to essential life-saving medicines. That is, politicizing the right to health care has empowered South African citizens. As the need for treatment literacy grows with hospitals and clinics expanding ART services in other provinces, TAC has now shifted its national focus to assume greater responsibility at the provincial and district levels (Robins, 2004; TAC, 2005a)⁵⁶. Lessons from TAC's activities in the Western Cape should be applied to other provinces that are not fully engaging with this organisation as yet.

When considering the role of TAC and the psycho-social support models being implemented in the Western Cape ART programme, a new kind of contract appears to be materializing between patients and health care providers. As Schneider and Coetzee (2003:1) note:

"This contract is premised on very high levels of understanding, treatment literacy and preparation on the part of users, the establishment of explicit support systems around users, and community advocacy processes that promote the rights of people living with HIV/AIDS. The responsibility for adherence is given to the client within a clear framework of empowerment and support."

This translates into more time and resources than is typical in a current patient and health worker relationship (Kovsted, 2005). Each of the support models outlined above have different implications from financial and human resources perspectives (Pienaar *et al.*, 2006). There is a need for further evaluation of these options to determine the most effective, efficient and sustainable approach as the programme continues to expand and patient

⁵⁵ Goemaere, 2006, personal comm., 18 July; Naidoo, 2006, personal comm., 7 August; Toms, 2006, personal comm., 13 July.

⁵⁶ TAC now has six provincial offices based in the Western Cape, Gauteng, KwaZulu-Natal, Eastern Cape, Limpopo and Mpumalanga and five district offices all of which are served by volunteers who conduct educational campaigns in their respective areas (TAC, 2005a).

numbers increase. Furthermore, when determining the most suitable model of care it is important to also ensure that it will have broader applicability within delivery of primary health care services -- a view touted by the PGWC and the City of Cape Town -- providing support for adherence to medications for other infectious and chronic diseases, such as TB and diabetes⁵⁷. This learning is critical to ensure health systems strengthening and continued success in this area in the Western Cape, as well as for other provinces that are only now beginning scale-up activities.

Finally, while WHO as well as the *National Antiretroviral Treatment Guidelines* strongly recommend extensive psycho-social support mechanisms as are implemented in the public sector roll-out in the Western Cape (DOH, 2004; WHO, 2004a), there is some indication from the Western Cape that high adherence rates can be maintained without these extensive measures of support. A study conducted amongst 289 patients presenting at the University of Cape Town's (UCT) HIV clinics, which serve largely indigent populations, revealed that adherence to ART was 93.5% in the absence of any dedicated adherence counselling service, structured adherence support or formal adherence intervention (Orrell *et al.*, 2003). This directly challenges arguments that ART must be delivered in resource-poor contexts with extensive adherence support mechanisms⁵⁸. With the public health risks being so high in the event of low adherence rates to HIV/AIDS medicines, it is well-founded that the PGWC (as well as the national and global responses) are exercising caution by instituting extensive support systems. Furthermore, these support systems are addressing broader socio-cultural barriers and stigma that permeate beyond adherence to drugs. Nevertheless, the findings from UCT's HIV clinics offer the possibility for successful adherence rates across South Africa, particularly in largely rural provinces such as the Eastern Cape, KwaZulu-Natal and Limpopo that are constrained by weaker health systems and poorer access to health care by their populations⁵⁹ (Castro-Leal, 1999) -- all inhibiting factors in the provision of resource intensive support systems that actively link clinics with communities.

⁵⁷ Cloete, 2006, personal comm., 8 August; Toms, 2006, personal comm., 13 July.

⁵⁸ For example, Wendo (2003) and Farmer *et al.* (2001) promote a Directly Observed Treatment (DOT) strategy for HIV/AIDS treatment by paralleling this to the management of Multi-Drug Resistant Tuberculosis in resource-poor contexts through a longer term "DOTS-Plus" intervention. (Directly Observed Treatment Short-course (DOTS) of Tuberculosis is a strategy that involves political commitment, good quality diagnosis, good quality drugs, short-course chemotherapy given under direct observation and systematic monitoring and accountability (WHO, 2005c).)

⁵⁹ Residents in these provinces have to travel the longest time to obtain medical attention (Castro-Leal, 1999).

Leadership and Management Model

At the core of the Western Cape ART's scale-up and success has been strong leadership and management at the provincial government level (Naimak, 2006) -- a model heralded by all implementation partners as best practice and warranting replication in other provinces. The political will to ensure access to HIV/AIDS treatment in the province has been firmly demonstrated through the commitment of provincial government financial resources to this effect, as well as the inclusion of all role players and partners in programme design and implementation. In particular, Dr. Grimwood⁶⁰ of ARK reflects that:

“[The programme] was established [by the PGWC] on a modicum of trust with the implementing partners, that was built on previous relationships and [was] not coming with a political agenda, and [was] not coming with a research agenda.”

When referring to scale-up of ART programmes, Schneider and Coetzee (2003:1) note that:

“Political management is as important as technical design. The process of implementation needs to [be] supported by a rigorous communication strategy aimed at preparing and ensuring the buy-in of all the actors who will be implicated in the process of implementation.”

The Western Cape provincial government has worked to achieve this by bringing together both managers and clinicians *from the beginning* into a common decision-making structure that meets regularly and determines the policy directions of the programme (Abdullah, 2005b)⁶¹. As new sites are opened in the province, those managers and health care practitioners join this structure, as do partners (*ibid*). The goal has been to consistently marry the challenges between delivery of treatment to patients with managerial issues such as budgets, human resources and procurement and supply chain management. The PGWC observe that this management model has fostered a detailed level of planning, transparency and, more importantly, joint ownership in addressing problems as well as in claiming credit for the successes of the programme (*ibid*)⁶². All informants noted that this has resulted in a “can do” approach to implementation that is seen at all levels -- from management to clinicians.

⁶⁰ Grimwood, 2006, personal comm., 10 July.

⁶¹ Slingers, 2006, personal comm., 9 August.

⁶² Cloete, 2006, personal comm., 8 August; Slingers, 2006, personal comm., 9 August.

Moreover, Dr. Fareed Abdullah, former Deputy Director General and Head of the AIDS programme in the Western Cape Province, was praised by most informants for his brave leadership and was attributed as the force behind the programme's standing success. He has been perceived by some as not only having the courage to begin the first PMTCT programme in 1999 -- against national policies at the time -- but also the vision to enter into a partnership with MSF to initiate research on implementation of ART at the primary care level (Naimak, 2006). In addition, Dr. Abdullah had the foresight in 2003 to apply to the GFATM for a grant -- subsequently generating substantial resources for the province that have greatly facilitated the successful scale-up of ART in the Western Cape (*ibid*). Dr. Maartens⁶³ of Groote Schuur hospital reflects on the role that Dr. Abdullah has played:

“He saw the need, drove the programme, [and] worked the system. [He] didn't break any rules and was smart. He took ownership of things instead of having donors parachuting in and out.”

Dr. Goemaere⁶⁴ of MSF also pertinently comments that:

“Fareed was the real driver behind [the programme]...Fareed was the visionary.”

⁶³ Maartens, 2006, personal comm., 29 June.

⁶⁴ Goemaere, 2006, personal comm., 18 July.

CHAPTER 4:
Key Challenges Confronting the Western Cape
HIV/AIDS Treatment Programme

While the South African ARV programme has been acknowledged by the Joint Civil Society Monitoring Forum⁶⁵ (JCSMF) as succeeding in many respects, it has been noted that “it needs to be infused with a permanent sense of urgency to drastically increase the numbers on treatment and to strengthen health resources and systems” (JCSMF, 2006b:1). A recent study assessing the availability and utilization of HIV services across South Africa revealed that the process of scaling-up ART is seemingly accentuating historic inequalities in health care access with poorer areas unable to effectively scale up the response even with the availability of extra resources (Scott *et al.*, 2005). In this context, it is widely acknowledged that in order to effectively address issues in equity of access and, thus, reach public health goals, a wider strengthening of health systems is required (EQUINET, 2004; McCoy, 2003). Moreover, unless policy makers attend to issues of equity, otherwise efficient public health HIV/AIDS treatment interventions may prove to be of limited effectiveness (Scott *et al.*, 2005) with limitations in access to care having a major impact on ART programme outcomes (Pienaar *et al.*, 2006). Policy directions on ARV allocation are critically important given that these decisions essentially determine who will live and who will die. In order to achieve public health goals and foster accountability, it is imperative that an open public policy debate and a fair process is conducted to inform the selection of such policies, and that any trade-offs in equity in access are made transparent and actively deliberated by all stakeholders (Daniels, 2005; McCoy, 2003; Rosen *et al.*, 2005).

⁶⁵ Launched in 2004, the Joint Civil Society Monitoring Forum consists of civil society organisations that are closely monitoring and assessing the implementation of the national Operational Plan.

In the following sections, I will discuss these two intertwined challenges that are confronting the Western Cape programme in the medium and long-term: Ensuring equitable and universal access to ARVs and achieving health systems strengthening. It is important to note that while there were a limited number of treatment slots during the pilot phase of the ART programme -- necessitating a triage approach to implementation -- as the programme now expands towards universal access, this, in theory, should no longer be a constraint. In this context, this research has identified a number of policy and implementation gaps that could hinder the ultimate realization of the goal of universal access. While the reality on the ground is that the capacity to scale-up still remains a challenge in the province -- resulting in the continuing use of rationing systems -- as the PGWC now enters its second phase of expansion towards universal access, the gaps in achieving equitable access generated from this research become of the utmost importance. Moreover, given the Western Cape's longer history in implementing ART, many insights can be drawn from these to inform policy directions and implementation in other provinces.

For the purposes of the ensuing discussion and analysis, the following definition of equity as it relates to health will be utilized (Stewart *et al.*, 2004:51):

"The absence of potentially remediable, systematic differences in one or more aspects of health across socially, economically, demographically, or geographically defined population groups or subgroups. Seeking equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair."

Fostering Equitable and Universal Access to ARVs

The PGWC has shown that a universally available HIV/AIDS treatment programme is within reach in South Africa (Abdullah, 2005a & 2005b). By December 2005, 55.7% of adults and children that are estimated to need ART treatment in the province were undergoing therapy (Nattrass, 2006a). Furthermore, it is expected that coverage rates for children will surpass 90% in 2006 as a result of the massive decrease in childhood infections attributable to the PMTCT programme (Abdullah, 2005b). However, with the Western Cape Province needing to expand the programme four-fold in the next five years to prevent an increase in morbidity and mortality (Pienaar *et al.*, 2006), increasing coverage, enrolling new patients on ART and equitably reaching the diverse range of populations in the province that need it remains the most formidable challenge of the programme.

For one, the Western Cape Province is nearing its full capacity of treatment numbers that the current national-approved budget of the *2006-2007 PGWC Business Plan* will allow for -- a maximum of approximately 22,500 patients (PGWC & UCT, 2006). Partners note that there is, hence, an urgent need for an increase in budgetary allocation in this area from national government as well as from other provincial and external sources if possible⁶⁶. The PGWC, however, remain confident that this will not be a constraint to expanding access. Dr. Cloete⁶⁷ of the PGWC notes that:

“It’s fine. I have got no problem with that. We have a clear process [with national]. And I think the process that we engage in with national is a good one and it is very clear. So I am not particularly over worried about that process.”

Nevertheless, this impending negotiation with national government vis-à-vis the budget remains the key determinant of the PGWC’s ability to further expand treatment and coverage.

In addition, TAC observes that the strict national guidelines for the accreditation of ART sites are posing a further barrier for expanding access and that they need to be re-visited within national dialogues⁶⁸. While other informants did not identify this as a barrier to expansion, accreditation of sites has been documented by some as slowing the implementation process in different provinces (Abdool Karim & Abdool Karim, 2005; Abdullah, 2005b; TAC & ALP, 2004 & 2005).

At the provincial level, current programme strategies are still challenged to reach all those that need ART in the province. To consider this, in the following sub-sections key strategies that the PGWC has employed will be discussed, namely, the selection of ART sites, the criteria for choosing patients, whether men and women are being appropriately targeted and reached as well as the programme’s nutrition component. For this analysis, it is important to note that the Western Cape Provincial *Antiretroviral Treatment Protocol* has patient selection criteria in line with the *National Antiretroviral Treatment Guidelines*. This includes, in addition to clinical eligibility for treatment, the collective consideration of further criteria such as geographical access to the site, disclosure, past history of adherence, alcohol

⁶⁶ Boulle, 2006, personal comm., 27 July; Hassan, 2006, personal comm., 11 July; Mthathi, 2006, personal comm., 17 July; Toms, 2006, personal comm., 13 July; Wood, 2006, personal comm., 7 August.

⁶⁷ Cloete, 2006, personal comm., 8 August.

⁶⁸ Mthathi, 2006, personal comm., 17 July.

and drug dependency and mental state (Provincial Administration Western Cape, 2004:4-5). Furthermore, while not explicitly stated in the *Antiretroviral Treatment Protocol*, Dr. Abdullah, former Deputy Director General of the PGWC, has documented that literacy levels are also being considered as eligibility requirements in the PGWC ART programme (Abdullah, 2005a & 2005b:253). In theory, none of these criteria are supposed to be exclusive and an assessment of the patient is done by the clinical team before a decision is made (Provincial Administration Western Cape, 2004).

Geographical Access

The provincial government has taken a strategic approach to scaling-up ART by limiting the number of ART sites to 40 or 50 in secondary Community Health Clinics (CHCs) and tertiary hospitals. The basis for this lies in that sufficient technical expertise does not exist at every clinic, community health service and hospital, so the government has opted for pooling expertise and focussing management and training on a more manageable number of sites (Abdullah, 2005b). Using this strategy, the PGWC has been able to reach as many people as possible in the shortest amount of time. Moreover, by limiting the number of practitioners prescribing ARVs, it is hoped that “liberal prescribing practice” will be averted and that the criteria for selection of patients will be more closely followed (Abdullah, 2005b:253). This approach essentially aims to prevent drug resistance in patients (and, thus, the wider community), by ensuring that patients that are most likely to adhere to treatment and be retained in care are selected for ART.

Furthermore, in an effort to promote equitable geographical access to ARVs while meeting public health goals, the decision as to where to open sites has been guided by antenatal prevalence rates in the province (with emphasis on high prevalence areas), existing expertise and infrastructure as well as geographical location⁶⁹. For example, while the West Coast of the province is under-populated with lower prevalence rates, given the lack of clinics in these areas some ART sites have, nonetheless, been opened in the region⁷⁰. Moreover, the PGWC observe that nearly every sub-district in the province has coverage with at least one ART site⁷¹.

⁶⁹ Maartens, 2006, personal comm., 29 June; Osler, 2006, personal comm., 30 June; Slingers, 2006, personal comm., 9 August.

⁷⁰ Osler, 2006, personal comm., 30 June.

⁷¹ Slingers, 2006, personal comm., 9 August.

Many scholars recognize that the scale-up of ART programmes must be initiated in better equipped and resourced hospitals and clinics (that are usually urban-based), and then expanded as fast as possible to other areas (Geffen *et al.*, 2003; Kovsted, 2005; Natrass & Geffen, 2003; Stewart & Loveday, 2005; WHO, 2004b). While this may contribute to worsening existing health inequalities, it is often seen as an initial unavoidable consequence of going to scale (Kovsted, 2005; Ntuli *et al.*, 2003; Stewart & Loveday, 2005). In the Western Cape, prospective ART patients that live far from the limited number of designated sites, particularly in rural areas, are at a great disadvantage when it comes to accessing treatment and continuity of care (Abdullah, 2005b)⁷². Furthermore, TAC and the AIDS Law Project (ALP), in monitoring the implementation of the PGWC programme, also observe that this is a particular problem for children needing treatment. Ms. Hassan⁷³ of ALP notes that:

“The whole issue of secondary and tertiary sites being the main nodes of treatment is a particular problem for children. If you look at the numbers of children on treatment most of them are concentrated in four, big urban hospitals. The issue then is what about children who can’t access those four sites?”

Moreover, even when prospective patients do present at one of the ART sites and are eligible for treatment from a clinical perspective, they may not be accepted in the programme for fear of low adherence given the need for regular follow-ups and their lack of proximity to the health service. Until the PGWC is able to effectively extend ART sites to these areas, it is critical that this programme address logistical issues, such as transportation, child care and time away from income-generating activities, in order to remove the barrier of physical isolation and ensure that all eligible patients can have access to these life-saving drugs (WHO, 2004b). Addressing transport barriers for rural populations is also stipulated in the *Antiretroviral Treatment Protocol*. In the absence of this, limiting the number of service sites will favour those who live nearby as well as households that have the resources to travel (Rosen *et al.*, 2005).

⁷² Cloete, 2006, personal comm., 8 August; Goemaere, 2006, personal comm., 18 July; Hassan, 2006, personal comm., 11 July; Mthathi, 2006, personal comm., 17 July.

⁷³ Hassan, 2006, personal comm., 11 July.

To date, no formal guidelines for enabling the policy of providing transport for far-flung communities have been developed in the Western Cape⁷⁴. Dr. Grimwood⁷⁵ of ARK notes that:

“Means of access to get transport support, to get your hospitals to waive the [clinic user] costs -- people still get charged -- [are lacking]. There is a lack of information on the ground and a lack of guidelines. The policy has not been translated into guidelines.”

Ms. Hassan⁷⁶ of the ALP further elaborates on the challenge of paying transport costs to reach distant ART sites as well as clinic user fees:

“There is transport, which nobody is addressing and nobody is attending to, and then there is the issue of user fees where people have to pay up to R70-75 per visit if they [are employed]. So some people are getting billed for the treatment [and paying transport costs].”

While the PGWC cites some examples in a few districts of using ambulances to bus patients to ART sites for HIV/AIDS services one day a week⁷⁷, or TAC getting local businesses to help provide transport⁷⁸, these are, however, not sustainable and feasible long-term solutions. Until ART is made more available at the community level and additional sites are opened, inaccessibility due to distance will persist as a key barrier in achieving equitable and universal access. With the restructuring of the health care system in the Western Cape Province in line with the *Comprehensive Service Plan for Health Care 2010*, the PGWC now plans to focus on decentralizing ART sites to the district level in the hope of removing this barrier⁷⁹. Nevertheless, in the interim, guidelines to enable the transport policy should be pursued to allow for more eligible patients to access this service, as well as to ensure that patients are not unduly paying for both transport and clinic user fees.

⁷⁴ Goemaere, 2006, personal comm., 18 July; Grimwood, 2006, personal comm., 10 July; Hassan, 2006, personal comm., 11 July; Maartens, 2006, personal comm., 29 June; Mthathi, 2006, personal comm., 17 July; Naidoo, 2006, personal comm., 7 August; Toms, 2006, personal comm., 13 July.

⁷⁵ Grimwood, 2006, personal comm., 10 July.

⁷⁶ Hassan, 2006, personal comm., 11 July.

⁷⁷ Osler, 2006, personal comm., 30 June; Slingers, 2006, personal comm., 9 August.

⁷⁸ Mthathi, 2006, personal comm., 17 July.

⁷⁹ Cloete, 2006, personal comm., 8 August.

In addition, the Western Cape Province is facing other challenges in reaching vulnerable groups with ART provision due to geographical barriers and the limited selection of ART sites. For example, the ALP has identified that most prisoners in the province are not getting effective access to HIV/AIDS treatment and that prison hospital clinics have not been prioritized for accreditation -- despite the public health HIV/AIDS crisis being seen in South Africa's jails⁸⁰. While prisoners might be transported to some outside accredited facility for ART occasionally, those that are waiting trial and cannot afford or are denied bail have no access at all and often spend long periods in this judicial limbo, while their health deteriorates greatly⁸¹. This would point to the need for prison facilities to be prioritized for accreditation as the province continues its roll-out campaign.

Furthermore, there is a challenge in ensuring continuity of care and adherence in patients who regularly move between neighbouring provinces. For example, partners observe that there is a large population of people from the Eastern Cape who move to Cape Town for work but go back to the Eastern Cape for several months every year⁸². While potentially administratively cumbersome, Dr. Toms of the City of Cape Town DOH and Prof. Wood of the Desmond Tutu HIV Centre consider the need to institute a cross-provincial system that allows patients to begin treatment in one province and continue to receive medications and counselling in another -- even if just temporarily⁸³. Dr. Toms notes that:

"We have acknowledged [this challenge] at the national level. The need to be able to find a way to relate that. In a sense, we could maybe phone the clinic [in the Eastern Cape] or warn them or somewhere make sure that the connection happens. Because it is not happening even in TB -- let alone ART."

Such a system, however, would necessitate political will at provincial levels as well as effective tracking systems within ART delivery services in both provinces.

⁸⁰ Hassan, 2006, personal comm., 11 July.

⁸¹ Hassan, 2006, personal comm., 11 July.

⁸² Boulle, 2006, personal comm., 27 July; Grimwood, 2006, personal comm., 10 July; Maartens, 2006, personal comm., 29 June; Toms, 2006, personal comm., 13 July; Wood, 2006, personal comm., 7 August.

⁸³ Toms, 2006, personal comm., 13 July; Wood, 2006, personal comm., 7 August.

Patient Selection Criteria

When considering equity in access to treatment, it is important to interrogate some of the psycho-social patient selection considerations in the treatment guidelines. In particular, while the many benefits of having the active support of a ‘treatment buddy’ of sorts are widely acknowledged in ensuring continuity of care for ART patients, the strongly recommended disclosure criterion raises some concerns. *Firstly*, and foremost, by evoking disclosure in an environment burdened by stigma and discrimination⁸⁴, many people may not voluntarily come forward to get tested and to accept treatment (Stewart *et al.*, 2004; Van Dyk & Van Dyk, 2003)⁸⁵. While some research studies are beginning to reveal how PLWHA are negotiating positive experiences of disclosure, addressing stigma and gaining support in a productive manner (Almeleh, 2004; Kahn, 2004), stigma and discrimination persists as a challenge in most communities. *Secondly*, such a criterion for consideration for treatment creates inconsistency and inequity between ART provision in the public sector as compared to in private practice where there is no disclosure policy. Since the public sector serves 84% of the population consisting mainly of the uninsured and poor (Health Systems Trust, 2005), this, in effect, creates a disparity where those of higher socio-economic levels can buy their anonymity, and those that are poorer must either relinquish the hope of lifesaving medicines or face the potential backlash that may result from disclosing their HIV status. *Finally*, a medical ethical dilemma remains in that a required disclosure of status to a family member or to a support group breaches confidentiality regarding “highly sensitive medical information” (Macklin, 2006:317). Moreover, because ART programmes in other countries do not require such disclosure, such as in Malawi (MOH, 2003) and in Zimbabwe (MOHCW, 2003), this suggests that drug compliance can be achieved without such a criterion and that individual rights are being unnecessarily infringed upon (*ibid*).

⁸⁴For example, in December 2003, Lorna Mlofane, a TAC volunteer, was murdered in Khayelitsha. There is substantial evidence that this was because she was openly HIV positive (TAC, 2004).

⁸⁵Booyesen, 2006, personal comm., 20 July; Hassan, 2006, personal comm., 11 July.

While research shows that in the MSF Khayelitsha clinics, nobody who meets the clinical criteria is ever denied treatment for non-disclosure (Coetzee & Nattrass, 2004), it is unclear whether this is the situation across other sites in the province. Moreover, although the selection process for ART has generally moved away from outright acceptance or denial towards preparing medically eligible patients to become ‘treatment-ready’ and to comply with adherence criteria, the disclosure criterion is still problematic. Some partners note that there have certainly been cases of sick AIDS patients who have trouble finding someone they trust to disclose to, and this extended process of acquiring a ‘treatment buddy’ has, in effect, denied them lifesaving treatment in a timely manner (Fox & Goemaere, 2006)⁸⁶. In addition, although disclosure is *strongly recommended* in the policy, in the process of this research it became clear that many health care providers have interpreted this as *required* to allow for treatment. The need for health care providers, including counsellors, to adopt an approach of *flexibility* when considering this criterion is critical⁸⁷.

For example, Dr. Maartens⁸⁸ of Groote Schuur hospital emphasizes that:

“People need to either disclose or join a support group. If somebody has not disclosed to anybody they don’t well, and they are under enormous stress and are isolated, and that is not a good idea. But I think we need to be flexible about it because it is problematic with stigma because stigma does still exist but, hopefully, it is being broken down slowly. I think [the policy recommendation] is an excellent idea as long as it is flexible.”

Dr. Grimwood⁸⁹ of ARK further notes that:

“If someone is completely adamant that they are not going to disclose, you can’t hold them back from treatment, you just can’t do it, it’s just a violation...We try not to push that [criterion], we [rather] try and encourage it.”

⁸⁶ Booyesen, 2006, personal comm., 20 July; Goemaere, 2006, personal comm., 18 July; Mthathi, 2006, personal comm., 17 July.

⁸⁷ Booyesen, 2006, personal comm., 20 July; Goemaere, 2006, personal comm., 18 July; Grimwood, 2006, personal comm., 10 July; Hassan, 2006, personal comm., 11 July; Maartens, 2006, personal comm., 29 June; Naidoo, 2006, personal comm., 7 August.

⁸⁸ Maartens, 2006, personal comm., 29 June.

⁸⁹ Grimwood, 2006, personal comm., 10 July.

In addition, Ms. Hassan⁹⁰ of the ALP even recommends that:

“It is enough if you can disclose to your health care worker and the nurse. It is important for people to be able to disclose to someone, but if the circumstances means that they can’t, you can’t deny them getting access to treatment because they are in a position where they can’t tell another family member. I think it will take time before people will be able to tell other people. The programme is new... there is still a lot of stigma and discrimination, people still see HIV as a death sentence.”

Moreover, Dr. Goemaere⁹¹ of MSF remains ambivalent about this criterion and pertinently notes that:

“The counsellors are judgemental and normative in terms of abiding to the ‘rule’ [of disclosure] and to the text. If [patients] are not ready to disclose to anybody or to their partner....we ask the counsellor to help them identify someone in a support group. [Strongly recommending disclosure] is [however] an issue. It’s a whole debate. While one of the building blocks of HIV treatment is confidentiality; we are proactively anti-confidential... in what we practice here.”

While further research is required to better understand what factors might prevent disclosure, how those on treatment in the public sector overcame their fears of disclosure and how many people are being excluded from this programme because of this policy, it is also important to establish consistent and, thus, equitable disclosure policies in both the public and private health care systems. That is, when enrolling patients on treatment, a strongly recommended disclosure guideline should be integrated for consideration within private care practice as well, *or* this criterion should be removed from public sector implementation of ART altogether.

In addition, the patient selection criteria of literacy and lack of alcohol and drug dependency also deserve further consideration. While these are all extremely important factors that could potentially disrupt adherence to ARVs, it is important to consider available evidence that demonstrates this as well as alternative approaches to outright exclusion. In the Western Cape, misuse of alcohol and drugs is implicated in 18.4% of all deaths in the province, indicating the widespread level of alcohol and drug abuse (Cummins, 2002). Moreover, illiteracy and high levels of alcohol and drug abuse are pervasive in lower socio-

⁹⁰ Hassan, 2006, personal comm., 11 July.

⁹¹ Goemaere, 2006, personal comm., 18 July.

economic classes⁹² implying that this ART programme is potentially not adequately reaching the poorest of the poor because of its selection policy. This seems particularly ironic given the established literature demonstrating the link between increased vulnerability to HIV/AIDS and lower socio-economic status (Fenton, 2004; Head, 1992; Kalichman *et al.*, 2005; McCoy, 2003; Stillwaggon, 2002 & 2003). That is, in effect, the very populations that most likely need ART are least likely to be able to access it.

While the Western Cape ART programme conducts referrals to detoxification and rehabilitation centres for people actively abusing alcohol and/or drugs, with the view that they should first be treated for substance abuse before they can begin ARV treatment (Provincial Administration Western Cape, 2004), it is highly possible that many of these patients will never be able to benefit from ART. For one, there are not many substance abuse treatment centres in the province⁹³. In addition, some partners observe that these patients often get lost from the health system or may greatly deteriorate in health or even die in the time it takes to undergo extensive drug rehabilitation⁹⁴. Moreover, when considering the PGWC's ability to adequately deal with alcohol and substance abuse in the context of provision of ART, Dr. Grimwood of ARK⁹⁵ notes:

"The [health] system cannot see it...If you are not geared for it as a system, you can't read it...It is bizarrely, you know, quiet [on this issue]. It is scary that we kind of walk with blinkers on."

In a context like the Western Cape, where research has shown how rampant drug and alcohol abuse is (Cummins, 2002; HSRC, 1998; SACENDU & MRC, 2006), it is imperative to consider some other policy options.

⁹² The legacy of apartheid persists in the new South Africa with 70% of the poor living in the former apartheid homelands (Castro-Leal, 1999). These populations are most vulnerable to alcohol and drug abuse which has been shown to be associated with poverty and higher levels of unemployment and crime (HSRC, 1998). Moreover, South Africa's matriculation results show poor performance overall and continued marked differences along racial and socio-economic lines (May, 1998).

⁹³ Goemaere, 2006, personal comm., 18 July; Grimwood, 2006, personal comm., 10 July; Hassan, 2006, personal comm., 11 July; Maartens, 2006, personal comm., 29 June; Mthathi, 2006, personal comm., 17 July.

⁹⁴ Goemaere, 2006, personal comm., 18 July; Grimwood, 2006, personal comm., 10 July; Mthathi, 2006, personal comm., 17 July; Wood, 2006, personal comm., 7 August.

⁹⁵ Grimwood, 2006, personal comm., 10 July.

The WHO's *Guidance on Ethics and Equitable Access to HIV Treatment and Care* (2004b:29) clearly states that special efforts are required to ensure equal ART access for the poor including "making the process of selection of patients as egalitarian as possible". Moreover, WHO (2004b:30) advises that:

"Making presumptions about patients' inability to adhere to treatment and then denying them access to ART is ethically problematic because denials based on unreliable predictions amount to unfair discrimination, and non-adherence is associated with conditions of greatest need."

While a research project at the Chris Hani Baragwanath hospital in Johannesburg suggested that socio-behavioural factors such as alcoholism can be impediments to adherence (Schneider, 2003), with ART scale-ups being a recent event globally, there is still very little evidence that demonstrates that criteria such as drug and alcohol abuse anticipate future adherence with any reliability (WHO, 2004b). In the absence of evidence-based criteria for future adherence, decisions to exclude potential patients from the ART programme are subject to stereotyping and discriminatory practices (Macklin, 2006; Ware *et al.*, 2005). For example, Dr. Goemaere⁹⁶ observes that:

"[In Khayelitsha], there is definitely discrimination [by health care staff] towards those people [who abuse alcohol and drugs]. [In the first year], there was an initial agreement that there were 180 [treatment] slots and, at that time, we had a whole selection committee with scoring sheets...scoring people to give priority [for ARV provision]. In that time, an alcoholic, male, single -- no way. It was completely discriminatory but it was linked to a limited number of slots. Nowadays, supposedly, we are not limited by the number of treatment slots [anymore]. It is a real question but [discrimination] is happening....Anyone who has serious substance abuse, and is known to have that abuse, there is no institution to come out to. There. There is a serious mistake. And counsellors are extremely judgemental."

Moreover, there is evidence suggesting that health care providers have limited success in predicting adherence generally (Wood, 2005), and such selection processes become problematic for public sector programmes aiming to achieve universal access (Myer & El-Sadr, 2004; Von Schoen Angerer *et al.*, 2001). Critically, provider assessments of 'treatment readiness', or lack thereof, should not be used as a means to ration access to treatment (Gebrekristos *et al.*, 2005).

⁹⁶ Goemaere, 2006, personal comm., 18 July.

Even if it was possible to accurately determine future adherence amongst people who abuse alcohol and drugs, the principles of fairness and right to equality would require special measures to improve adherence and retention in care in patients that encountered difficulties - - as opposed to excluding them from the programme (Myer & El-Sadr, 2004; WHO, 2004b). Dr. Slingers of the PGWC notes that doctors at ART sites should, at the very least, use every resource available to them to facilitate adherence support in such cases⁹⁷. For example, in other countries it has been shown that HIV-infected Injecting Drug Users who receive comprehensive care with respect to drug dependence, mental health and HIV, usually adhere to their treatment plans as well as other patients (WHO, 2004b). While this would require a more resource intensive model of care, the psycho-social community support system being implemented in Gugulethu or the Patient Advocate model developed by ARK offer a potential starting point (see pages 43-44 for details on these models). Moreover, a co-ordinated multi-sector approach, particularly between the Department of Social Services and the DOH, is essential to have success in this area⁹⁸. While the provincial government is not expected to *immediately* ensure access to everyone in the scale-up of ART, the Constitution (Government of South Africa, 1996: Chapter 2, Article 27 (2)) requires the state, with respect to the right to health care services, to:

“Take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of [this] right.”

That is, the provincial government is obliged to put in place a plan, with accompanying timeline and allocated resources, to ensure that the above-mentioned barriers to accessing the ART programme are addressed and equity is, ultimately, achieved.

Finally, the links between the provision of ART and treatment of opportunistic infections of TB (and MDR-TB) merits attention -- particularly for the Western Cape that has the highest rate of TB in South Africa (Abdullah, 2005a). For example, in Khayelitsha, more than half of TB sufferers are co-infected with HIV (WHO, 2003). National and Western Cape treatment protocols dictate that someone who presents with co-infection of HIV and TB must first be treated for TB before they can begin ART due to the adverse reactions of taking

⁹⁷ Slingers, 2006, personal comm., 9 August.

⁹⁸ Booysen, 2006, personal comm., 20 July; Cloete, 2006, personal comm., 8 August; Hassan, 2006, personal comm., 11 July; Mthathi, 2006, personal comm., 17 July; Slingers, 2006, personal comm., 9 August.

both therapies (DOH, 2004; Provincial Administration Western Cape, 2004). This poses an extremely difficult challenge for the province in ensuring access to ART in these contexts where TB rates are so high, and the need for evidence-based clinical guidelines on the most favourable time to initiate ART in TB patients has been identified as a priority (JCSMF, 2006b). Moreover, Dr. Maartens of Groote Schuur hospital suggests a more nuanced approach to dual treatment looking at each individual case by case⁹⁹. He reflects that:

“TB is our biggest problem and it is difficult to manage them jointly. There are all sorts of problems. It is nuanced and I think that is how [the policy] should be.”

Although outside the scope of this present study, further detailed research in this area is vital.

Gender Equitable Promotion and Programme Strategies

Historically, reproductive health services have exclusively targeted women and their specialized needs (Cooper *et al.*, 2004). Furthermore, HIV/AIDS advocacy, prevention and treatment efforts have often focussed on reaching women presenting at health services around pregnancy (Ipas, 2005). Actively targeting men in HIV/AIDS programmes is critical since dominant gender¹⁰⁰ norms of masculinity not only subjugate women and girls and increase their vulnerabilities to HIV/AIDS, but also endanger men’s own sexual and reproductive health because of, or even *despite*, their greater power (Gupta *et al.*, 2003; Morrell, 2001; Peacock & Botha, 2004; Population Council, 2001; Selikow *et al.*, 2002). Abdool Karim (2005: 253) defines these gender norms:

“In most societies women are cast in a subordinate, dependent and passive role where the ideal virtues include virginity, motherhood, obedience, and ignorance – particularly about their bodies. In contradistinction, masculinity is cast in terms of aggression, dominance, independence and invincibility, where the key virtues are strength, courage and virility.”

⁹⁹ Maartens, 2006, personal comm., 29 June.

¹⁰⁰ Gupta (2000:18) defines gender as “the widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which women and men interact with each other”.

These prevailing gender norms have shown to determine both men's and women's ability to access health care services for treatment of HIV/AIDS. In this context, health programme strategies must take into consideration gender relations¹⁰¹ vis-à-vis HIV/AIDS programming. For example, research has shown that women's access to health care may be limited due to men's control of a woman's finances, mobility and the decision-making process as to whether she should seek HIV/AIDS health services (Gupta, 2000; Population Council, 2001; UNAIDS, UNFPA & UNIFEM, 2004). Moreover, unless a woman is pregnant and referred for HIV/AIDS care through maternal services, gender norms that encourage virginity in women and the popular notion that infection is linked to promiscuity could also deter women from accessing services for fear of stigma and discrimination (Gupta, 2000; UNAIDS, UNFPA & UNIFEM, 2004). Significantly, however, recent studies in South Africa indicate that men access HIV/AIDS testing and treatment services later than women, viewing this health-seeking behaviour as a sign of weakness (Peacock, 2005). Cultural notions of manhood, combined with stigma, a preference to use traditional medicine and logistical issues around attending a clinic when employed, have also all been found to be barriers to men acknowledging their HIV status and seeking medical treatment (Beck, 2004). Moreover, in South Africa, seven out of ten adults accessing ART are women (JCSMF, 2006b), most of whom are directly referred to ART from maternal services. Similar data is also seen at the provincial level across ART sites in the Western Cape (Bekker *et al.*, 2006; Coetzee & Nattrass, 2004; Pienaar *et al.*, 2006).

This data points to gender inequity in provision of ART services within the public sector in the Western Cape. Dr. Maartens¹⁰² of Groote Schuur hospital reflects that:

¹⁰¹ Agarwal (1994:51) defines gender relations as "the relations of power between women and men which are revealed in a range of practices, ideas and representations, including the division of labour, roles and resources between women and men, and the ascribing to them of different abilities, attitudes, desires, personality traits, behavioural patterns, and so on".

¹⁰² Maartens, 2006, personal comm., 29 June.

“One of the biggest challenges is where are the men? They are just not coming forth for care. I think the biggest problem is that our health care messages have further stigmatized men and made it virtually impossible for men to access care. The first programme that the province supported here was for children. Why are children more important than adults? And then the next programme was for their mothers. Women and children [seen] as the victims. If they are the victims, what are men? The perpetrators. Now there are men out there who are perpetrators and there are also men out there who are infected and are not rapists or whatever. But, unfortunately, the message that has gone out is that men are the problem and women are not.”

Furthermore, in general, clinics are not ‘male-friendly’ and the majority of health care staff are women -- a factor that has shown to further alienate men from accessing VCT and treatment services¹⁰³. Dr. Goemaere¹⁰⁴ of MSF observes that:

“Counsellors are very judgemental. It is dangerous. It is a real issue...And there is an enormous prejudice against males. The health services are run by women...They are making the decisions in terms of inclusions and there is a prejudice against men because there is a certain stereotype of men...The whole picture of men...is absolutely traumatic.”

In addition, in some sites in the Western Cape with huge backlogs, pregnant women with low CD4+ counts are given priority and are allowed to “jump the queue” for ART services (Abdullah, 2005b). While it is critical that pregnant women obtain ARVs in a timely manner to protect their health and that of their child, this practice does place health care providers in an “ethical quandary” vis-à-vis other sick patients already worked up and waiting for treatment (Abdullah, 2005b:261). When considering different rationing systems Rosen *et al.* (2005) conclude that prioritizing treatment and care for pregnant women is an extremely effective and efficient strategy but does create a system that reduces equity in access. McCoy (2003) goes so far to state that it promotes pregnancy as a means to access treatment. That is, targeting women for ART through maternal services prioritizes them over men as well as women who are not currently bearing children (Rosen *et al.*, 2004). While it is certainly merited that such an approach would be utilized in an environment of limited resources and capacity, as well as in the long-term interests of averting the growing

¹⁰³ Booysen, 2006, personal comm., 20 July; Goemaere, 2006, personal comm., 18 July; Maartens, 2006, personal comm., 29 June; Mthathi, 2006, personal comm., 17 July; Naidoo, 2006, personal comm., 7 August.

¹⁰⁴ Goemaere, 2006, personal comm., 18 July.

population of HIV/AIDS orphans, as the PGWC begins to expand access to ART, new strategies that reach these other populations will need to be employed in an effort to achieve equitable and, ultimately, universal access.

While health services and promotion policies are currently not adequately targeting the inclusion of men into ART in the Western Cape, the PGWC warns that the ART programme is already operating at full capacity, and that a coordinated outreach effort to bring in all eligible patients -- including the missing men -- could flood the system¹⁰⁵. Dr. Cloete of the PGWC further explains that:

“I think that we are in the business of setting up the health systems in response to the needs of the people. We know there is an unmet health need amongst men. Until we see models to tell us this is the way to do it we are not going to embark on any fancy strategies to get men into the service, until somebody demonstrates to us a good model to put our energies and money into. We are struggling just as it is to meet the need pitching up at our doorsteps.”

Some informants felt that, despite these resource limitations, given the high prevalence of HIV in men in South Africa as well as gender norms that make both men and women increasingly vulnerable to HIV/AIDS, the need to actively target men as partners in HIV/AIDS prevention messages, VCT and treatment is, nonetheless, critical. Re-orienting PMTCT and subsequent ART referrals towards families (UNAIDS, UNFPA & UNIFEM, 2004), such as in the PMTCT-Plus initiative in Langa, increasing awareness and activism on HIV/AIDS amongst men such as with the *Men as Partners* programme¹⁰⁶, reaching men who are already in the hospital system and ensuring that VCT is readily available both within and outside the health care system are some key strategies to addressing this gender inequity. Further, family-oriented treatment programmes may not only increase the likelihood that men use these services but also that *all* patients adhere to ARVs and are retained in care, therefore, leading to better clinical outcomes (Myer & El-Sadr, 2004). Moreover, the JCSMF (2006b)

¹⁰⁵ Cloete, 2006, personal comm., 8 August.

¹⁰⁶ Driven by the need for a more effective response to HIV/AIDS and violence against women in South Africa, EngenderHealth and the Planned Parenthood Association of South Africa (PPASA) established a *Men As Partners (MAP)* programme. The overall goal of the programme is to increase men's involvement in HIV/AIDS related prevention, care and support activities by encouraging men to take an active stand against gender-based violence and for gender equality in their personal lives and in their communities (Peacock & Botha, 2004).

has also recently labelled reaching men as a critical challenge in the ARV roll-out and has called on government to urgently develop strategies that will effectively encourage men to access HIV/AIDS treatment and care services.

Recently, a shift has been seen in the Western Cape sites where ARK is working, where the percentage of women presenting for this service -- in relation to men -- has dropped from 75% to 59%¹⁰⁷. Dr. Grimwood of ARK attributes this change to:

“The fact that the women are getting better, remaining well, getting stronger, getting back to work, becoming more financially independent, and the men are becoming weaker and realizing that [ART] is something that they can get a hold off.”

Moreover, the PGWC has just embarked on a respondent-driven sampling research project to determine how a community-based platform can more effectively engage men and create a demand for health care services¹⁰⁸. In addition, the City of Cape Town DOH has been trying to actively target men at taxi ranks in Belville, and will do so later this year in Mitchell’s Plain (in collaboration with the Department of Transport of the City of Cape Town), as well as through STI clinics (traditionally ‘spaces’ for men) and at four non-clinic VCT centres¹⁰⁹.

Nutritional Support

It is important to note the critical role of nutritional support in an ART programme. Numerous studies have demonstrated a more rapid transition from HIV to AIDS in malnourished people as well as increased susceptibility to infectious diseases in general (Anabwani & Navario, 2005; Chandra, 1996; De Waal & Whiteside, 2003; Fawzi *et al.*, 2004; Stillwaggon, 2002; Van Lettow *et al.*, 2003; Visser, 2005). Moreover, in other countries, health outcomes on ART have proven to be sub-standard due to poor nutritional status (International HIV/AIDS Alliance, 2002). Sufficient food supplies have shown to be both preventative, in that they support healthy immune systems, and remedial, in that they are essential for drug treatment to be effective and reduce viral load (*ibid*).

¹⁰⁷ Grimwood, 2006, personal comm., 10 July.

¹⁰⁸ Cloete, 2006, personal comm., 8 August.

¹⁰⁹ Toms, 2006, personal comm., 13 July.

While the government of South Africa has plans to provide nutritional support to those who need it, through programmes such as the Nutrition Supplementation Programme for people living with TB and HIV/AIDS, the extent to which these policies are being implemented successfully is questionable (Ndlovu & Daswa, 2006a; TAC, 2006b; TAC & ALP, 2005). Furthermore, the Operational Plan holds the DOH accountable for provision of nutritional supplements for ARV patients, coordinating interdepartmental nutritional programmes and developing nutritional training materials (DOH, 2003:82-85). With regards to nutritional support for patients on ARV treatment, it (DOH, 2003:82) explicitly states that:

“The HIV and AIDS care and treatment programme envisages the provision of supplement meals to all people with clinical AIDS who are malnourished and are eligible for ARVs, and who do not have access to a secure food supply. Individuals with AIDS who are not food insecure, and who receive care and treatment through a service point, should be referred to one of the appropriate existing nutritional programmes for additional nutritional support, if indicated.”

To date, the Western Cape ART programme has not prioritized the provision of nutritional support for all patients on ARVs (Abdullah, 2005b). For one, the PGWC note that the administration of the nutrition programme is structurally separate from the ART programme and this has led to a challenge of coordination in implementation -- with eligible ART patients being referred from ART sites to clinics that offer the nutrition programme¹¹⁰. Moreover, Ms. Van Nierkerk, Assistant Director of the Integrated Nutrition Programme of the PGWC, observes that while the Nutrition Supplementation Programme budget was traditionally geared to target approximately 90% malnourished children and 10% adult TB patients, with the advent of ART this ratio of children to adults receiving nutritional supplements has shifted in favour of adults -- with approximately a third of ART patients currently receiving this service¹¹¹. This, however, has not been accompanied by an appropriate increase in budget to allow for this escalating demand in nutritional support¹¹². This means that not only is there a cap on capacity to provide this service to all ART patients that need it, but, in effect, for each adult on ART receiving food supplements, there will be a malnourished child who no longer can do so.

¹¹⁰ Cloete, 2006, personal comm., 8 August; Osler, 2006, personal comm., 30 June; Van Nierkerk, 2006, personal comm., 14 July.

¹¹¹ Van Nierkerk, 2006, personal comm., 14 July.

¹¹² Van Nierkerk, 2006, personal comm., 14 July.

While a policy was developed in 2005 to eliminate the referral system and allow for nutritional support for all patients who request it at the *actual* ARV sites in the Western Cape (Abdullah, 2005b), the PGWC note that budgetary and procedural processes are still being resolved¹¹³. Moreover, while the PGWC touts the establishment of the programme at 33 of the 44 ART sites, it also reflects that implementation remains challenged by the lack of dieticians and nutritionists in the province, persisting poor coordination amongst the programmes (“red tape”) as well as the fact that the administration of food supplements is still not being properly recorded in the registers by doctors at ART sites¹¹⁴. This makes it very hard to determine the effectiveness of this policy to date. Partners note that, in practice, this policy is not working at all and in some sites they are relying on the work of local NGOs and Community-Based Organisations (CBOs) to provide nutrition to food insecure ART patients¹¹⁵. In addition, until 2005, MSF itself provided nutritional supplements to pre-ART patients in Khayelitsha -- to try and stabilize HIV positive patients before beginning treatment -- but no longer does so with the government policy aimed at solely targeting patients actually on ARVs¹¹⁶.

With the recent DOH policy framework gearing towards decentralization of the PGWC ART programme, the PGWC emphasizes that in order to ensure smoother linkages between delivery of ART as well as the nutrition programme (traditionally based at the district clinic level), it is essential that ART services are now firmly integrated within district-level primary health care clinics¹¹⁷. With implementation of this strategy pending, an examination of how the effectiveness of the nutrition programme to date has affected adherence in the Western Cape programme, as well as any positive outcomes in therapy, is an important research question. Moreover, the possible implications of this vis-à-vis the provision of an equitable and universal programme are critical policy considerations given that patients from poorer households who are more likely to be malnourished may have less positive health outcomes than patients from more affluent settings.

¹¹³ Van Nierkerk, 2006, personal comm., 14 July.

¹¹⁴ Osler, 2006, personal comm., 30 June; Van Nierkerk, 2006, personal comm., 14 July.

¹¹⁵ Goemaere, 2006, personal comm., 18 July; Grimwood, 2006, personal comm., 10 July; Hassan, 2006, personal comm., 11 July; Khwaza, 2006, personal comm., 20 July.

¹¹⁶ Goemaere, 2006, personal comm., 18 July.

¹¹⁷ Cloete, 2006, personal comm., 8 August.

Health Systems Strengthening

In post-apartheid South Africa, the government has aimed to develop a more equitable national health care system through expanded access within a district-based system of primary health care that integrates clinical care with health promotion and disease prevention (Benatar, 2004; DOH, 2000). This primary care model places emphasis on the development of basic health care programmes such as antenatal care, child health and nutrition, immunization, and the “management of communicable disease and the treatment of chronic ailments” (DOH, 2000:3). Within such a health care model, numerous scholars emphasize the crucial importance of integrating an ART programme firmly within the public health primary health care system while strengthening systems for both ART as well as overall health care delivery (McCoy *et al.*, 2005; Nattrass & Geffen, 2003; Schneider & Coetzee, 2003; Stewart *et al.*, 2004; Stewart & Loveday, 2005; WHO, 2005a). ART programmes have even been conceptualized as *opportunities* for addressing underlying problems and transforming the public health system as a whole (Abdullah, 2005b)¹¹⁸.

In this context, scarce human resources and weak health systems, especially procurement and supply chain management (PSM) systems¹¹⁹ for HIV/AIDS drugs and diagnostics, remain some of the key barriers in rolling out ART (Gray, 2005; ITPC, 2006; Kober & Van Damme, 2004; Stewart & Loveday, 2005; TAC, 2005c; TAC & ALP, 2005; WHO, 2005a). Even though the Western Cape has scaled-up ART effectively, suggesting that these potential difficulties have been overcome, the province is still challenged in achieving overall health system strengthening at the primary care level¹²⁰. While it is certainly too soon to measure the effects of ART services on delivery of overall health care services, some are more sceptical than others. Dr. Toms of the City of Cape Town Department of Health notes that, if anything, it has greatly strained the existing primary health care service despite the reduction in morbidity events of HIV/AIDS patients¹²¹. This is discussed more below.

¹¹⁸ Mthathi, 2006, personal comm., 17 July; Wood, 2006, personal comm., 7 August.

¹¹⁹ Procurement and Supply Chain Management (PSM) refers to the complicated and intricate process of product selection, forecasting, procurement of quality assured drugs and diagnostics in sufficient quantities, inventory management, reliable and secure distribution to suppliers and monitoring and evaluation of the full PSM cycle to ensure rationale use (GFATM, 2005).

¹²⁰ Cloete, 2006, personal comm., 8 August; Mthathi, 2006, personal comm., 17 July; Naidoo, 2006, personal comm., 7 August; Toms, 2006, personal comm., 13 July.

¹²¹ Toms, 2006, personal comm., 13 July.

The Current ART Implementation Model in the Western Cape

The PGWC has committed itself to integrating the HIV/AIDS programme, including the ART programme, into the general public health system by allocating the additional resources from this programme into strengthening the health system instead of creating a vertical approach to HIV/AIDS service delivery¹²² (Ndlovu & Daswa, 2006b). While a horizontal model has been sought by the provincial government, as a result of the provision of ARVs being widely considered by experts as “far more complex than any other primary care intervention ever in the history of health care”¹²³, a strategy of specialized care has been utilized to date. Unlike in the primary care model, patients are referred directly from VCT sites, antenatal clinics, TB and STI local authority clinics to specialist ARV sites (Abdullah, 2005b). Moreover, while the national primary health care model essentially aims to empower services at the district level, because of the complexities of providing ART and the lack of capacity often at the local authority level, the PGWC has subsumed control¹²⁴ of the management of these services throughout the province¹²⁵. As such, this set-up, while deemed necessary by the PGWC and partners to allow for the rapid scale-up of this service¹²⁶, is in contradiction with a national vision of a district-based and driven system. Furthermore, agreements between PGWC and local authorities on this process are still being delicately defined. On reflecting on this model, Dr. Goemaere¹²⁷ of MSF raises concerns about the centralization of ART provision within the Provincial government-controlled sites, such as at hospitals or CHCs, as opposed to at the local authority level clinics, noting that:

¹²² A ‘vertical’ health model refers to developing a specialized service for a given health problem using dedicated health workers as compared to a ‘horizontal’ approach where a general health service aims to tackle overall health problems on a wide front and long-term basis (Mills, 2005).

¹²³ Maartens, 2006, personal comm., 29 June.

¹²⁴ To-date, the ART programme is not only financially and administratively managed by the PGWC but ART sites are set-up predominantly in PGWC-controlled hospitals (levels one, two and three) as well as Community Health Clinics (CHCs) -- as opposed to city-run district level clinics (Cloete, 2006, personal comm., 8 August).

¹²⁵ Boulle, 2006, personal comm., 27 July; Cloete, 2006, personal comm., 8 August; Grimwood, 2006, personal comm., 10 July; Mthathi, 2006, personal comm., 17 July.

¹²⁶ Boulle, 2006, personal comm., 27 July; Cloete, 2006, personal comm., 8 August; Hassan, 2006, personal comm., 11 July; Mthathi, 2006, personal comm., 17 July; Toms, 2006, personal comm., 13 July.

¹²⁷ Goemaere, 2006, personal comm., 18 July.

“[Setting up] a centralized [ART] unit within a tertiary-based hospital -- that was the worst place to put it actually, and as a result, they were very quickly saturated and also started to face adherence problems because it is far away and it is costly....it is very well known that people can not afford to go there on a regular basis because of the taxi fares.”

While the PGWC stand firm on the need to have initiated ART in this manner, they do wholly recognize these physical constraints posed by the current model¹²⁸.

Furthermore, the current ART delivery model in the province (coined the “Rolls-Royce ART service”) is also viewed by some as too costly and, thus, as non-sustainable -- diverting additional resources that should be strengthening the overall primary health care system into a specialized service for HIV/AIDS. For one, Dr. Goemaere of MSF and Dr. Naidoo and Dr. Toms of the City of Cape Town DOH observe that most ART staff positions were strategically classified at a senior level (Senior Medical Officers or Principal Medical Officers), luring a cadre of health care providers from within the public health system with the attractive recruitment packages, and leaving gaping vacancies in other areas of health care provision¹²⁹. While ARK have employed a strategy in the sites they work in of only recruiting ART health care providers from private sector or that are in retirement, this phenomenon of ‘poaching of staff’ by the PGWC from the general health services is certainly perceived across all the sites. Dr. Cloete¹³⁰ of the PGWC fully acknowledges this:

“Because of the way that we implemented, and we fully acknowledge that as a department, and there is a reason why we did it. We did it full willingly knowing what we were doing. We implemented it as a vertical model. So because we implemented it as a vertical model the impact on other services would be negative. It has dedicated people, they don’t get involved with the rest of the services, and we are dragging staff and training staff from other services into the ARV programme. Maybe if you do a very crude analysis at each of the sites you could say that people on ARVs get better treatment, and other clients get worse treatment. So all of those things. We are fully aware that if you do an assessment that is what you’ll find.”

¹²⁸ Cloete, 2006, personal comm., 8 August.

¹²⁹ Goemaere, 2006, personal comm., 18 July; Naidoo, 2006, personal comm., 7 August; Toms, 2006, personal comm., 13 July.

¹³⁰ Cloete, 2006, personal comm., 8 August.

In addition, the current system is doctor-driven and, hence, more costly, and is not sustainable if the province is to continue expanding treatment to achieve universal access. For example, current modelling of the provincial epidemic -- using the present ART health delivery model -- estimates that 42 ART doctors will be needed in Khayelitsha by 2010 if the province is to keep up with demand¹³¹. The PGWC as well as partners agree that this model is not feasible and that a nurse-driven approach¹³² must be adopted (Pienaar *et al.*, 2006)¹³³. However, research has shown that, even with the current ART model, the increase in nurses since the advent of the ART programme has been inadequate to cope with the demands of administering ART as well as tending to the increasing number of AIDS-sick patients (Natrass, 2006a). Moreover, with only 31.5% of all nurses trained in South Africa between 1996 and 2004 having registered with the South African Nursing Council (Subedar, 2005), a huge percentage of trained nurses are being 'lost' from the system -- a factor that could greatly impede the province's ability to successfully roll-out a nurse-driven ART programme (Natrass, 2006a). Nevertheless, there is now consensus among the PGWC and partners that it is essential to recruit and retain more nurses within the health system, as well as to broaden their scope of practice, in order to ensure the efficient and effective expansion of ART (Pienaar *et al.*, 2006). In this context, a failure to invest in nurses *sufficiently* will seriously constrain the province's ability to continue to increase ART provision (Natrass, 2006a).

Finally, as a conditionality of the GFATM grant, and in an effort to have greater control over the procurement and supply chain management of HIV/AIDS medicines -- and safeguard against stock-outs and theft -- the PGWC set up a parallel system comprising a separate ARV depot (Abdullah, 2005b; Naimak, 2006)¹³⁴. This has been highly criticized by some who claim that the resources should have been used to strengthen the functioning of the Cape Medical Depot that houses all other medicines and diagnostics procured by the DOH, instead of unnecessarily building a new infrastructure, hiring new staff and creating more bureaucracy to manage the HIV/AIDS treatment programme. While the PGWC are firm on

¹³¹ Boulle, 2006, personal comm., 27 July; Goemaere, 2006, personal comm., 18 July.

¹³² A nurse-driven model based on WHO's *Integrated Management of Adolescent and Adult Illness* (IMAI) model designed to make ART delivery more effective and efficient in the context of human resource shortages should be explored (WHO, 2004c). This model includes a down-shifting of tasks from doctors to nurses to community health workers (*ibid*).

¹³³ Boulle, 2006, personal comm., 27 July; Cloete, 2006, personal comm., 8 August; Goemaere, 2006, personal comm., 18 July; Hassan, 2006, personal comm., 11 July; Naidoo, 2006, personal comm., 7 August; Slingers, 2006, personal comm., 9 August; Toms, 2006, personal comm., 13 July.

¹³⁴ Cloete, 2006, personal comm., 8 August.

the importance of having set up a separate system initially, as the province has gained more experience and expertise in the large-scale procurement of HIV/AIDS drugs, there are now plans to merge the separate ARV PSM system into the already existing provincial supply chain and depot in the next two years¹³⁵.

Some believe that while taking the health systems strengthening approach would have meant slower initial delivery, and lower treatment numbers, it would have had multiple positive and reinforcing effects on the delivery of all primary health care services -- including ART -- in the long-term. Dr. Toms¹³⁶ of the City of Cape Town DOH reflects that, in effect:

“[A vertical approach to HIV/AIDS] is dangerous. It works but at what costs? Then children are not getting immunized. You actually unwind a lot of the good work that you have been doing from the outset. You don't ultimately save lives. You save people who are HIV positive but you are killing kids with diarrhoea because they can't access the service now because there is no staff. Because they all went to the ARV programme because they pay more. That is what de facto happened...The more you 'verticalize' the programme the more you encourage stigma almost because you are making it special and different both amongst patients and health care workers and, of course, the guys controlling the funds...So you see the danger of vertical funding becomes more and more again the 'specialness' and now you can zap it, or drive it depending on the political changes.”

Persisting Challenges in ART Health System Delivery

Amidst the challenge of overall health systems strengthening, the PGWC is still facing a number of obstacles in ensuing effective ART delivery itself. As noted previously, the HIV/AIDS ART provincial budget is swiftly reaching its maximum, meaning that there will be a cap on infrastructure and staffing as well as the quantity of HIV/AIDS drugs and diagnostics that can be purchased, and, thus, patients who can receive ART. Ultimately, the enrolment capacity of the programme is a function of the number of staff and any limits in this area will preclude the province from reaching more people who are in desperate need of ART. Furthermore, the PGWC and TAC note that the province continues to struggle to recruit the medical staff that it needs to sustain the scaling-up of this programme, particularly

¹³⁵ Cloete, 2006, personal comm., 8 August; Slingers, 2006, personal comm., 9 August.

¹³⁶ Toms, 2006, personal comm., 13 July.

in the rural areas (TAC, 2005c)¹³⁷. Finally, physical infrastructure has shown to be a constraint in the effective expansion of ART services at some sites in the province (Abdullah, 2005b; Bekker *et al.*, 2006; Pienaar *et al.*, 2006). There are also generally too few facilities in many areas to effectively cater to the health needs of communities (TAC, 2006b). For example, Khayelitsha with a population exceeding 500,000 is only served by three ART clinics, whereas the U.N.'s Inter-Agency Standing Committee recommended population to clinic ratio would require at least ten (*ibid*). These factors are all greatly curtailing the ability of the Western Cape to achieve universal access to ART.

A Way Forward: A Decentralised and Integrated Approach

In light of all these challenges, and in line with the recently-endorsed *Comprehensive Service Plan for Health Care 2010*, the PGWC has renewed its priority to effectively integrate ART within other primary care services and, thus, achieve overall health systems strengthening¹³⁸. While the vertical approach was vital to the rapid provision of ARVs, and to meet external donor's requirements of achieving treatment numbers (Nattrass, 2006a), it is now widely agreed that in the medium and long-term these services should be fully integrated into the primary health care district-level system and that an integrated continuum of care should be provided. Moreover, the PGWC and partners note that a number of hospitals and sites in the province are already reporting that they are running at full capacity and can't cope with the increasing demand for ART¹³⁹. This has been evidenced by the continuing deferment of eligible patients and long waiting times (Pienaar *et al.*, 2006). For example, Dr. Goemaere¹⁴⁰ of MSF observes that:

“The numbers are a big issue in terms of access [in Khayelitsha]. You have to queue early morning despite the fact that there are appointments, and now to be admitted there, to get a folder number and a specific folder, the appointments are given for in three or four months time. [The sites are] saturated. The only possibility is to decentralize further to existing city clinics -- we have eleven here in Khayelitsha.”

¹³⁷ Mthathi, 2006, personal comm., 17 July; Slingsers, 2006, personal comm., 9 August.

¹³⁸ Cloete, 2006, personal comm., 8 August.

¹³⁹ Cloete, 2006, personal comm., 8 August; Goemaere, 2006, personal comm., 18 July; Naidoo, 2006, personal comm., 7 August; Slingsers, 2006, personal comm., 9 August; Toms, 2006, personal comm., 13 July.

¹⁴⁰ Goemaere, 2006, personal comm., 18 July.

In this context, the PGWC, in collaboration with the City of Cape Town DOH, have developed a new ART model using the analogy of a 'hub-and-spokes' system¹⁴¹. This is beginning to be implemented this year. In this approach, a central hub clinic (the current PGWC hospital or CHC ART site) is established in an urban centre with smaller spoke district-run clinics spread throughout a defined geographical area. Patients needing ARVs and living in a hub's catchment area would be referred to the hub for a treatment readiness evaluation, education and drugs. After a period of successful treatment through the hub, 'green patients' who are stabilized on ARVs with no complications and adherence difficulties will be referred back to their local spoke where their care will be managed. Patients will only return to the hub for specialized care or to address severe complications that may arise. This model is primarily nurse-driven and would move monitoring and care as well as provision of ARVs into the district-level primary health care system. Moreover, staffing would be strengthened at the local level in this model with the view to have ART fully integrated within district-level clinics and, in time, actual ART uptake processed at the clinic level as well -- through doctor outreach and, eventually, by nurses¹⁴². Only ART patients with special needs would then be referred to the hub site.

Through such an approach to ART, not only will geographical barriers to access be removed but stigma around seeking HIV/AIDS treatment and care is likely to be reduced as these services are 'normalized' within the context of other health services (Pienaar *et al.*, 2006). Most critically, the PGWC and partners agree that the service will now be placed where it is needed most -- at the district community level. Only by *fully* mobilising the existing health system -- including at the district level -- can universal access be achieved (Loewenson & McCoy, 2004; Schneider, 2003). By the end of 2006, the PGWC and City of Cape Town DOH plan to implement this model in nine local authority clinics¹⁴³. While two of these nine sites aim to expand ART services managed by MSF in Khayelitsha, Dr. Goemaere¹⁴⁴ of MSF reflects that to-date:

¹⁴¹ Cloete, 2006, personal comm., 8 August; Slingers, 2006, personal comm., 9 August; Toms, 2006, personal comm., 13 July.

¹⁴² Please note that there is still disagreement on how to implement this model vis-à-vis staffing at the local clinic level as compared to at the CHC and hospital levels. Some are arguing for full clinical teams including ARV specialist doctors to be placed at the local level as opposed to establishing a referral system whereby nurses at the clinic level refer patients to the central hub ART site for necessary care by ART doctors (Bouille, 2006, personal comm., 27 July; Pienaar *et al.*, 2006).

¹⁴³ Cloete, 2006, personal comm., 8 August; Naidoo, 2006, personal comm., 7 August.

¹⁴⁴ Goemaere, 2006, personal comm., 18 July.

*“It has been a fantastic waste of opportunity...From a technical point of view, we need the City service. They have huge capacity and they are dealing with TB and STIs which are two very important things [for ART provision], and **they are there.**”*

With the impending transition towards local ownership of the HIV/AIDS treatment programme, the PGWC has developed plans to build more infrastructure to support the ART scale-up, as well as to better integrate the ART programme with TB services at the local level -- in an effort to ensure that both these programmes are more efficient and that effective continuum of care is provided to patients¹⁴⁵. A study of both the TB and HIV services in Khayelitsha indicated that despite active cross-referrals between both programmes, there was unnecessary overlap of activities, duplication of services and under-utilization of staff (Coetzee *et al.*, 2004b). In addition, recent research has highlighted that there is a general sentiment amongst health care providers that integration of HIV and TB services would assist in ‘demystifying’ the ART programme and further normalizing it within district health services (Pienaar *et al.*, 2006:5). As a result, in order to achieve this and optimise available financial and human resources, several sites have piloted the integration of HIV and TB services. For example, in Hout Bay, the City of Cape Town DOH has effectively integrated these services using a nurse-driven approach and generating enduring high TB cure rates and positive ART treatment outcomes¹⁴⁶. This makes this site an important model for other clinics as the province expands this integrated approach. Furthermore, in collaboration with ARK, the integration of PMTCT, TB services and paediatric care into ART services is also beginning -- forming the second phase of PGWC’s partnership with this NGO¹⁴⁷.

¹⁴⁵ Cloete, 2006, personal comm., 8 August; Slingsers, 2006, personal comm., 9 August.

¹⁴⁶ Naidoo, 2006, personal comm., 7 August.

¹⁴⁷ Grimwood, 2006, personal comm., 10 July.

This process of integration aims to ultimately achieve health systems strengthening while maintaining ART programme outcomes. Dr. Cloete¹⁴⁸ of the PGWC explains:

“If you take a timeline for integration, we must do integration from the point of view of maintaining the outcomes. If you follow that logic, how would this integrated programme now start benefiting the rest? By maintaining the outcomes, and what has been good about [the ART programme] you can then start spreading it to the other [health services].”

In addition, Dr. Grimwood¹⁴⁹ of ARK remains optimistic about this strategy to integrate and move ART into a more horizontal approach:

“I think it is very possible to have a fully integrated system with time. What we need to do is to understand [that you have to] get the systems in place and get clinicians, patients and clinic staff familiar with process and stuff so you can then, therefore, start incorporating it; But there are certain things you have to do [first]. It's like a recipe that you need to follow. If you don't follow it, you end up with problems. If you try and get that process embedded in how you manage it, than you can take it anywhere.”

Significantly, partners note that this call to integrate ART more effectively within the existing primary health care system has paved the path for a historical and unprecedented collaboration between the City of Cape Town and PGWC. This marks the beginning of a new kind of partnership between government at different levels, and many hope it will inform such cooperation in other areas of Health.

¹⁴⁸ Cloete, 2006, personal comm., 8 August.

¹⁴⁹ Grimwood, 2006, personal comm., 10 July.

Conclusion

Within the context of a burgeoning HIV/AIDS pandemic, access to ARV treatment remains one of the most pertinent goals in mitigating the impact of this disease on people infected and affected by HIV/AIDS and, ultimately, in halting its spread. While ART is widely available in developed countries, access to treatment remains inadequate in low and middle income countries. Currently, it is estimated that only 20% of people who need ART in the developing world have access to it. Moreover, most resource-poor countries are struggling to implement treatment programmes in the face of numerous infrastructure and systems barriers as well as socio-economic inequalities.

In South Africa, a history of oppression, social disenfranchisement, the migrant labour system and poverty have contributed to the spread of the epidemic with estimated adult prevalence rates of 18.8% and antenatal prevalence rates of 30.2%. One of the worst affected countries in the world, South Africa continues to have the highest number of people living with HIV estimated at 5.5 million within a general population of 47.43 million. Alarming, HIV/AIDS is also now the primary cause of death in the nation. Within such a bleak context, access to life-saving ARVs has become critical, not only to meet public health goals of halting the further spread of the epidemic and to reducing morbidity events among PLWHA, but also to safeguard the rights and welfare of individuals, families and communities at large.

Amidst national, regional and global advocacy calling for access to ARV treatment, combined with falling HIV/AIDS drugs prices and increasing funding by bilaterals and multilaterals, the Western Cape Province has been in the forefront of making treatment available to those who need it. Long before a national policy for HIV/AIDS treatment was in place, the PGWC courageously pioneered implementation of PMTCT in 1999, and expanded this in 2001 to providing ART to the broader community in select pilot sites -- making the project the first to use ARVs in government health facilities outside the context of clinical trials. Moreover, the PGWC had the foresight to cultivate partnerships with donors such as MSF and the Desmond Tutu HIV Centre, as well as other academic and research institutions, allowing the province to gain expertise in administration of ARVs while vital research on implementation was being conducted. When the national government finally announced the Operational Plan for national provision of ART through the public sector in late 2003, the

PGWC already had a wealth of experience and expertise in implementation to draw from.

Since 2004, the PGWC has successfully scaled-up ART provision throughout the province. It is considered to be a highly effective and successful programme as evidenced by its capacity to quickly and effectively treat a substantial number of PLWHA, while yielding continuing positive health outcomes in patients and measurable reductions in AIDS-related morbidity and mortality. By December 2005, it was estimated that 55.7% of people that need ART in the province had access to it as compared to a national average of 10% for South Africa. Within South Africa, this programme has laid the basis for the rest of the country to follow suit. Within the global activist and donor environment, the Western Cape Province has demonstrated to the international community that the use of ARVs at primary care level in resource-constrained settings is feasible, affordable and replicable.

This research has shown that there are a number of key factors that have contributed to the success of the PGWC's ART programme. *Firstly*, the Western Cape Province has historically stronger health systems in place than most other provinces. As such, it was able to speedily initiate ART provision where the infrastructure exists. In addition, the HIV epidemic in the Western Cape Province is at an earlier stage than in other provinces with a provincial antenatal prevalence rate of 15.7% -- almost half the national average. This, combined with the epidemic's predominant concentration in the urban areas, allowed the PGWC to swiftly target urban centres achieving high coverage rates due to the lower numbers of people that need ART in the Western Cape -- as compared to other provinces. This may present a challenge for provinces whose infrastructure is not as well developed and whose populations are largely rural such as in KwaZulu-Natal.

Secondly, the province's head-start in administering ARVs through the PMTCT programme and, later, in pilot government-run sites has been cited as the cornerstone of the Western Cape's success in scaling-up. Important lessons in ARV provision, developing guidelines and managing case loads were drawn from this initial experience.

Thirdly, this dissertation has shown how key partnerships with NGOs, academic and research institutions and, most importantly, donors, have allowed the Western Cape Province to forge new ground, conduct vital research and speedily expand coverage. The PGWC's successful application to the GFATM in 2004 further fuelled this momentum.

Fourthly, when considering the continuing positive health outcomes in patients on this programme, this research has shown that the strategies used in the province to ensure adherence to medications and retention in care have been central to this success. While there are numerous patient-centred adherence support models currently being implemented in the province, they all boast successful patient outcomes. Some of these models are more resource-intensive than others and further research is still required to determine the most feasible and cost-effective approach to support the further expansion of ART in the province. Importantly, the role of TAC in treatment literacy for ARV patients and for the community at large has been attributed as pivotal to the province's continuing high adherence rates and, thus, successful health outcomes.

Finally, the leadership and management model of the PGWC has been heralded as a best practice by all partners. This model has fostered a sense of inclusiveness, partnership and joint accountability in implementation of ARV treatment provision. In particular, Dr. Fareed Abdullah, former Deputy Director General and Head of the AIDS programme in the Western Cape Province, was praised by most informants for his brave leadership and was perceived as the force behind the programme's standing success.

While there are many best practices that can be gleaned for other provinces from this case study, this dissertation has shown that some important challenges persist in the medium and long-term even in the Western Cape. In particular, with national commitments to the progressive achievement of socio-economic rights and, thus, universal access to ART, ensuring equitable and timely access to everyone who is medically eligible for ART remains a key obstacle and is an essential determinant of the ultimate success of the programme. Moreover, in order to effectively address issues in equity of access, and expand coverage, a wider strengthening of health systems is required.

This research has identified a number of policy and implementation gaps that could hinder the realization of the goal of universal access. While there were a limited number of treatment slots during the pilot phase of the ART programme -- necessitating a triage approach to implementation -- as the programme now expands towards universal access, this, in theory, should no longer be a constraint. However, the reality on the ground is that ART sites are at full capacity and are still unable to consider all patients equitably. Moreover, the PGWC is near to expending its entire 2006-2007 budget, effectively creating a cap on the

number of patients that can be enrolled on ART next year if this budget is not swiftly increased by national government and through other donors. Nonetheless, the PGWC remains confident that budgetary issues will not constrain the continuing expansion of ART in the province. In this context, as the PGWC enters its second phase of expansion, with plans for decentralization and broader health systems strengthening, the gaps in achieving equitable access generated from this research become of the utmost importance.

This dissertation has identified several challenges for the Western Cape Province in achieving equitable and, ultimately, universal access. *Firstly*, with a limited number of ART sites mainly concentrated in the urban areas, geographical access to HIV/AIDS treatment remains a barrier for communities living far away, particularly in the rural areas. Until the PGWC is able to effectively decentralize provision of ARVs, the current policy dictates that transport issues to ART sites should be co-ordinated and resolved through the PGWC. To date, this has not been implemented. Thus, this dissertation recommends that appropriate guidelines to enact this policy provision are developed. In addition, this research found concerns over access barriers of prisoners in the province as well as of patients who move back and forth between the Eastern Cape and Western Cape.

Secondly, the patient selection criteria that consider lack of disclosure and the abuse of alcohol and drugs as constraints to treatment-readiness were also found to be problematic in ensuring equitable access. It was found that in a number of ART sites, the strongly *recommended* disclosure criterion was seen as a *requirement*, resulting in patients often accessing ART very late or, sometimes, too late. An approach of flexibility has been recommended when considering disclosure. In addition, within the context of private practice having no disclosure criterion, this research recommends that equitable and, thus, consistent policies vis-à-vis disclosure are adopted for both public and private practice. Furthermore, while there are legitimate concerns regarding the effects of alcohol and drug abuse on ensuring adherence to medications and continuity of care, this research has found that patients that are referred to detoxification or rehabilitation centres often get lost from the system or die due to the limited support services in this area. In line with WHO, this dissertation recommends that additional support services are instituted in time to address such barriers to successful treatment as opposed to outright exclusion.

Thirdly, the current ART programme has been challenged to reach men effectively, given that the majority of ART patients are women referred through maternal services. Some informants felt that the PGWC was not adequately implementing health promotion strategies that would draw men into clinics. Moreover, persisting and traumatic stereotypes of men by clinic staff also appear to be posing as a barrier to access. This research recommends that a strategy be implemented to more effectively involve men in HIV/AIDS programming and to ensure that more men are fast-tracked to ART through the general hospital or clinic system in the way that pregnant women are with the PMTCT programme. In addition, approaches to target women that are not pregnant are needed as the PGWC continues to expand ART.

Finally, it is widely accepted that adequate nutrition is an essential component to achieving successful health outcomes on ART. This research shows that while the PGWC has a policy in place for provision of nutritional supplements, this has not been prioritized nor thoroughly integrated within the ART services, and the policy's effectiveness to date remains questionable. This has enormous repercussions vis-à-vis provision of an equitable and universal programme given that the poorest of the poor are most likely to be food insecure. This dissertation recommends that implementation of the provision of nutritional support is re-vitalized as well as prioritized within the PGWC's plans to decentralize and integrate ART.

Access to ARVs is a matter of life or death for PLWHA, so the choice of rationing systems that the PGWC utilizes in the scale-up of ART, such as selection of sites, patient selection criteria and targeting women through maternal services, are critically important. Moreover, government must put measures in place to address these constraints posed by policy decisions to expand ART -- building capacity in other areas to ensure universal access over time, and revising policies as appropriate to guarantee the progressive realization of the rights of all people who need ART.

Furthermore, this research shows that it is critical that treatment access is expanded in a way that strengthens the health system's capacity to provide ART as well as comprehensive primary health care services in a sustainable and equitable manner. The PGWC's vertical, doctor-driven and hospital and CHC-based approach to ART implementation, while deemed necessary for the speedy scale-up of the programme, is now seen by stakeholders as too costly and not sustainable in the medium and long-term. Moreover, this specialized vertical

approach has not contributed to overall health systems strengthening as yet and has been perceived by some as having drained the general health services. The PGWC's recently-endorsed strategy to move implementation of ART to the district-based level, and firmly integrate this within existing TB and other general health services, offers much hope to the ultimate realization of equitable and universal access as well as overall health systems strengthening.

Finally, in order to ensure that existing disparities in wealth and health are not further perpetuated and aggravated, the ART programme should move beyond the purely biomedical approach to adequately address social determinants, such as poverty, alcohol and substance abuse and gender relations, that could hinder access to ART as well as yield negative health outcomes. In line with the PGWC's current approach, this would, critically, involve the down-shifting and effective integration of ART within the district level health services, and would require a renewed commitment to working with other sectors to address these barriers. Only by adopting a multi-sectoral health activism that tackles both the systems in delivery as well as the broader political and socio-economic constraints, will the roll-out of ART in the Western Cape Province achieve universality, equity and social justice.

Works Cited

- Abdool Karim, Q. 2004. HIV Treatment in South Africa: Overcoming Impediments to Get Started. *Lancet*. 363:1394.
- Abdool Karim, Q. 2005. Heterosexual Transmission of HIV- The Importance of a Gendered Perspective in HIV Prevention. In *HIV/AIDS in South Africa*. Q. Abdool Karim and S.S. Abdool Karim (Eds.). New York: Cambridge University Press. 243-261.
- Abdool Karim, S.S., Abdool Karim, Q. & Baxter, C. 2003. Antiretroviral Therapy: Challenges and Options in South Africa. *Lancet*. 362:1499.
- Abdool Karim, S. S. & Abdool Karim, Q. 2005. The Future of the HIV Epidemic in South Africa. In *HIV/AIDS in South Africa*. Q. Abdool Karim and S.S. Abdool Karim (Eds.). New York: Cambridge University Press. 567-572.
- Abdullah, F. 2005a. Challenges to Treatment Rollout. Presentation to Critical Issues in the Study of HIV/AIDS and Society, University of Cape Town, 23 September 2005.
- Abdullah, F. 2005b. The Complexities of Implementing Antiretroviral Treatment in the Western Cape Province of South Africa. *Development Update*: 245-264.
- Absolute Return for Kids (ARK). 2005. Patient Advocate/Community Adherence Worker, Phase 2, Draft Training Module, June 2005. Cape Town: Absolute Return for Kids and Centre for Social Science Research, University of Cape Town.
- African Union (AU). 2006. *Universal Access to HIV/AIDS, Tuberculosis and Malaria Services by 2010. Africa's Common Position to the U.N. General Assembly Special Session on AIDS (June 2006)*. Special Summit of African Union on HIV/AIDS, Tuberculosis and Malaria, Abuja, Nigeria, 2-4 May.
- Agarwal, B. 1994. *A Field of One's Own: Gender and Land Rights in South Asia*. Cambridge: Cambridge University Press.
- Almeleh, C. 2004. *The Longlife AIDS-Advocacy Intervention: An Exploration into Public Disclosure*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, August 23].
- Anabwani, G. & Navario, P. 2005. Nutrition and HIV/AIDS in Sub-Saharan Africa: An Overview. *Nutrition*. 21:96-99.
- Baldwin-Ragaven, L., de Gruchy, J. & London, L.1999. *An Ambulance of the Wrong Colour: Health Professionals, Human Rights and Ethics in South Africa*. Cape Town: University of Cape Town Press.
- Barnett, T & Whiteside, A. 2002. *AIDS in the Twenty-First Century: Disease and Globalization*. New York: Palgrave Macmillan.

- Beck, D. 2004. *Men and ARVs: How Does being a Man Affect Access to Antiretroviral Therapy in South Africa? An Investigation Among Xhosa-Speaking Men in Khayelitsha*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, August 23].
- Bekker, L.-G., Myer, L., Orrell, C., Lawn, S. & Wood, R. 2006. Rapid Scale-Up of a Community-Based HIV Treatment Service. Programme Performance over 3 Consecutive Years in Gugulethu, South Africa. *South African Medical Journal*. 96(4):315-320.
- Benatar, S. R. 2004. Health Care Reform and the Crisis of HIV and AIDS in South Africa. *New England Journal of Medicine*. 351(1):81-92.
- Bernard, H. R. 1994. Participant Observation. In *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. London: Sage.
- Bourne, D. 2005. The Demographic Impact of HIV/AIDS. Presentation to Critical Issues in the Study of HIV/AIDS and Society, University of Cape Town, 12 August, 2005.
- Bradshaw, D *et al.* 2004. Unabated Rise in Number of Adult Deaths in South Africa. *South African Medical Journal*. 94(4):278-279.
- Butler, A. 2005. South Africa's HIV/AIDS Policy, 1994-2004: How Can It Be Explained? *African Affairs*. 104(417):591-614.
- Castro-Leal, F.1999. The Impact of Public Health Spending on Poverty and Inequality in South Africa. *South Africa: Poverty and Inequality, Informal Discussion Paper Series*. Washington DC: World Bank.
- Chandra, R.K. 1996. Nutrition, Immunity and Infection: From Basic Knowledge of Dietary Manipulation of Immune Responses to Practical Application of Ameliorating Suffering and Improving Survival. *Proc Natl Acad Sci USA*. 93:14304-14307.
- Cleary, S., Boulle, A., McIntyre, D. & Coetzee, D. 2004. *Cost-Effectiveness of Antiretroviral Treatment for HIV-Positive Adults in a South African Township*. Cape Town: Health Systems Trust, Médecins Sans Frontières & University of Cape Town.
- Coetzee, C. & Nattrass, N. 2004. *Living on AIDS Treatment: A Socio-Economic Profile of Africans Receiving Antiretroviral Therapy in Khayelitsha, Cape Town*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2005, November 15].
- Coetzee, D. *et al.* 2004a. Outcomes after Two Years of Providing Antiretroviral Treatment in Khayelitsha, South Africa. *AIDS*. 18(6):887-895.
- Coetzee, D. *et al.* 2004b. Integrating Tuberculosis and HIV Care in the Primary Care Setting in South Africa. *Tropical Medicine and International Health*. 9(6):A11-A15.

- Coetzee, D. *et al.* 2005. Effectiveness of the First District-Wide Programme for the Prevention of Mother-To-Child Transmission of HIV in South Africa. *Bulletin of the World Health Organisation*. 83(7):489-494.
- Cooper, D. *et al.* 2004. Ten Years of Democracy in South Africa: Documenting Transformation in Reproductive Health Policy and Status. *Reproductive Health Matters*. 12(24): 70-85.
- Coulson, N, *et al.* 1998. *Promoting Health in South Africa: An Action Manual*. Johannesburg: Heinemann.13-23.
- Cummins, P. 2002. Access to Health Care in the Western Cape. *Lancet*, 360: 49-50.
- Daniels, N. 2005. Fair Process in Patient Selection for Antiretroviral Treatment in WHO's Goal of 3 by 5. *Lancet*. 366:169-171.
- De Waal, A & Whiteside, A. 2003. New Variant Famine: AIDS and Food Crisis in Southern Africa. *Lancet*. 362:1234-1237.
- Department of Health, Republic of South Africa (DOH). 2000. *Primary Health Care Progress Report*. Pretoria: Department of Health.
- Department of Health, Republic of South Africa (DOH). 2003. *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa*. 19 November. Pretoria: Department of Health. [Online]. Available: <http://www.info.gov.za/otherdocs/2003/aidsplan.pdf> . [2006, May 3]
- Department of Health, Republic of South Africa (DOH). 2004. *National Antiretroviral Treatment Guidelines*. Pretoria: Department of Health.
- Department of Health, Republic of South Africa (DOH). 2005. *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2004*. Pretoria: Department of Health.
- Department of Health, Republic of South Africa (DOH). 2006a. *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2005*. Pretoria: Department of Health.
- Department of Health, Republic of South Africa (DOH). 2006b. *Republic of South Africa: Progress Report on Declaration of Commitment on HIV and AIDS. Prepared for United Nations General Assembly Special Session on HIV and AIDS*. Pretoria: Department of Health.
- Department of Health, Western Cape (PGWC). 2002. *The Provincial & District HIV Antenatal Survey 2001*. Cape Town: Department of Health.
- Department of Health, Western Cape (PGWC). 2003. *The Provincial & District HIV Antenatal Survey 2002*. Cape Town: Department of Health.

- Department of Health, Western Cape (PGWC). 2004. *The Provincial & District HIV Antenatal Survey 2003*. Cape Town: Department of Health.
- Department of Health, Western Cape (PGWC). 2005. *The Provincial & District HIV Antenatal Survey 2004*. Cape Town: Department of Health.
- Department of Health, Western Cape (PGWC). 2006. *Western Cape Antiretroviral Monthly Summary for June 2006*. Cape Town: Department of Health.
- Department of Health, Western Cape (PGWC) & University of Cape Town (UCT). 2006. *Monitoring of Antiretroviral Treatment in the Western Cape Province, South Africa. Quarterly Report, May 2006*. Cape Town: Department of Health.
- Dorrington *et al.* 2001. *The Impact of HIV/AIDS on Adult Mortality in South Africa. Technical Report*. Tygerberg: Medical Research Council.
- Dorrington, R. *et al.* 2004. *The Demographic Impact of HIV/AIDS in South Africa: National Indicators for 2004*. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.
- Egger, M *et al.* 2005. Antiretroviral Therapy in Resource-Poor Settings: Scaling Up Inequalities? *International Journal of Epidemiology*. 34:509–512.
- EQUINET (Southern African Regional Network for Equity in Health). 2004. Monitoring Equity and Health Systems Issues in ART Programmes in Southern Africa. Report of a Regional Meeting, Lilongwe, Malawi, 7-8 October.
- Farmer, P *et al.* 2001. Community-Based Approaches to HIV treatment in Resource-Poor settings. *Lancet*. 358:404-409.
- Fawzi, W. W. *et al.* 2004. A Randomized Trial of Multivitamin Supplements and HIV Disease Progression and Mortality. *New England Journal of Medicine*. 351:23-32.
- Fenton, L. 2004. Preventing HIV/AIDS Through Poverty Reduction: The Only Sustainable Solution? *Lancet*. 364:1186-1187.
- Fox, R. C. & Goemaere, E. 2006. They Call It “Patient Selection” in Khayelitsha: The Experience of Médecins Sans Frontières-South Africa in Enrolling Patients to Receive Anti-Retroviral Therapy for HIV/AIDS. *Cambridge Quarterly of Health Care Ethics*. 15:302-312.
- Friedman, S & Mottiar, S. 2005. A Rewarding Engagement? The Treatment Action Campaign and the Politics of HIV/AIDS. *Politics and Society*. 33(4):511-565.
- Gauri, V. & Lieberman, E. S. 2004. AIDS and the State: The Politics of Government Responses to the Epidemic in Brazil and South Africa. Development Research Group, World Bank. (Unpublished).

- Gebrekristos, H. T., Mlisana, K. P. & Abdool Karim, Q. 2005. Patients' Readiness to Start Highly Active Antiretroviral Treatment for HIV. *British Medical Journal*. 331:772-775.
- Geffen, N. 2001. Pharmaceutical Patents, Human Rights and the HIV/AIDS Epidemic. Treatment Action Campaign. TAC Discussion Document. [Online]. Available: <http://www.tac.org.za/Documents/ResearchPapers/wbcsdtlk.pdf> . [2005, December 20].
- Geffen, N., Natrass, N. & Raubenheimer, C. 2003. *The Cost of HIV/AIDS Prevention and Treatment Interventions*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, February 24].
- Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). 2005. *Guide to Writing the Procurement and Supply Management Plan. Version A*. Geneva: GFATM.
- Government of the Republic of South Africa. 1996. *Constitution of the Republic of South Africa*. Pretoria: Government of the Republic of South Africa.
- Gray, A. 2005. The Challenges of Implementing Antiretroviral Treatment in South Africa. In *HIV/AIDS in South Africa*. Q. Abdool Karim and S.S. Abdool Karim (Eds.). New York: Cambridge University Press. 524-537.
- Gruskin, S. & Tarantola, D. 2002. Health and Human Rights. In *Oxford Textbook of Public Health*. J. Last (Ed.). New York: Oxford University Press. 4.1:314-316
- Gupta, G.R. 2000. Gender, Sexuality, and HIV/AIDS: The What, the Why, and the How. *Women's Health Project Newsletter*. 36: 18-21.
- Gupta, G.R., Whelan, D. & Allendorf, K. 2003. *Integrating Gender into HIV/AIDS Programmes*. Geneva: WHO.
- Hassan, F. & Bosch, D. 2006. *Monitoring the Provision of ARVs in South Africa: A Critical Assessment*. ALP Briefing for TAC NEC, Cape Town, 17-18 January. University of Witwatersrand: AIDS Law Project.
- Head, J. 1992. Behavioural Assumptions about the Spread of HIV Infection in South Africa: Myth or Reality. *AIDS Bulletin*. 1(2):16-19.
- Health Systems Trust. 2005. *South African Health Review 2005*. Durban: Health Systems Trust.
- Herman, D. 2006. Cape Loses Top Fighter against AIDS as Abdullah Resigns Post. *Cape Times*. January 9.
- Heywood, M. 2004. The Price of Denial. *Development Update*. 5(3):93-122.
- Human Sciences Research Council (HSRC). 1998. *HSRC Research Points to a Complex Link between Drugs and Crime in South Africa*. [Online] Available: <http://www.hsrc.ac.za/media/1998/11/19981102.html>. [2005, December 20].

- Institute of Medicine. 2004. *Scaling Up Treatment for the Global AIDS Pandemic: Challenges and Opportunities*, Report Brief. [Online] Available: <http://www.iom.edu/Object.File/Master/21/270:0.pdf>. [2006, January 26].
- International HIV/AIDS Alliance. 2002. *Improving Access to HIV/AIDS Related Treatment*. Brighton: International HIV/AIDS Alliance.
- International Treatment Preparedness Coalition (ITPC). 2006. *Missing the Target. Off Target for 2010: How to Avoid Breaking the Promise of Universal Access. Update to ITPC's AIDS Treatment Report from the Frontlines. 24 May 2006*. [Online] Available: <http://dedi20a.your-server.co.za/alp/images/upload/ITPCreport24.05.06.pdf>. [2006, June 15].
- Ipas. 2005. *HIV/AIDS and Reproductive Health Sensitive and Neglected Issues: A Review of the Literature, Recommendations for Action*. Chapel Hill: Ipas.
- Joint Civil Society Monitoring Forum (JCSMF). 2006a. Assessment of the North-West Province ARV Rollout and the Private Sector's Contribution to Implementing HIV/AIDS Treatment and Care in SA. Resolutions of the 7th JCSMF Meeting, Orkney, North-West, 3 March.
- Joint Civil Society Monitoring Forum (JCSMF). 2006b. Consensus Statement. 8th JCSMF Meeting, Johannesburg, 9 June.
- Jones, P.S. 2004. When Development Devastates: Donor Discourses, Access to HIV/AIDS Treatment in Africa and Rethinking the Landscape of Development. *Third World Quarterly*. 25(2): 385-404.
- Kahn, L. 2004. *Experiences of HIV/AIDS Diagnosis, Disclosure and Stigma in an Urban Informal Settlement in the Cape Peninsula: A Qualitative Exploration*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html. [2006, August 23].
- Kalichman *et al.* 2005. Associations of Poverty, Substance Use, and HIV Transmission Risk Behaviours in Three South African Communities. *Social Science and Medicine*. 62:1641-1649.
- Kasper, T *et al.* 2003. Demystifying Antiretroviral Therapy in Resource-Poor Settings. *Essential Drugs Monitor*. 32:20-21.
- Kober, K & Van Damme, W. 2004. Scaling Up Access to Antiretroviral Treatment in Southern Africa: Who Will Do the Job? *Lancet*. 364:103-107.
- Kovsted, J. 2005. Scaling Up AIDS Treatment in Developing Countries: A Review of Current and Future Arguments. *Development Policy Review*. 23(4):465-482.
- Lange, J. M. A., Perriens, J., Kuritzkes, D. & Zewdie, D. 2004. What Policymakers Should Know about Drug Resistance and Adherence in the Context of Scaling-Up Treatment of HIV Infection. *AIDS*. 18(suppl 3):S69-S74.

- Leclerc-Madlala, S. 2005. Popular Responses to HIV/AIDS and Policy. *Journal of Southern African Studies*. 31(4):845-856.
- Lieberman, E.S. 2004. Department of Politics, Princeton University. (Unpublished). Quoted by Gauri, V. & Lieberman, E. S. 2004. AIDS and the State: The Politics of Government Responses to the Epidemic in Brazil and South Africa. Development Research Group, World Bank. (Unpublished).
- Loewenson, R & McCoy, D. 2004. Access to Antiretroviral Treatment in Africa. *British Medical Journal*. 328:241-242.
- Macklin, R. 2006. No Shortage of Dilemmas: Comment on "They Call It 'Patient Selection' in Khayelitsha". *Cambridge Quarterly of Healthcare Ethics*. 15:313-321.
- Mann, J. M. *et al.* 1999. Health and Human Rights. In *Health and Human Rights: A Reader*. J.M. Mann, S. Gruskin, M.A. Grodin & G.J. Annas (Eds.). New York: Routledge.16-21.
- Marshall, S.J. 2004. South Africa Unveils National HIV/AIDS Treatment Programme. *Bulletin of the World Health Organisation*. 82(1):73-74.
- May, J. (ed). 1998. *Poverty and Inequality in South Africa*. Report prepared for the Office of the Executive Deputy President and the Inter-Ministerial Committee for Poverty and Inequality. [Online] Available: <http://www.polity.org.za/html/govdocs/reports/poverty.html?rebookmark=1#5> [2005, December 20].
- McCoy, D. 2003. Health Sector Responses to HIV/AIDS and Treatment Access in Southern Africa: Addressing Equity. Health Systems Trust and EQUINET Discussion Paper Number 10, October 2003.
- McCoy, D *et al.* 2005. Expanding Access to Antiretroviral Therapy in Sub-Saharan Africa: Avoiding the Pitfalls and Dangers, Capitalizing on the Opportunities. *Global Health Concerns*. 95(1):18-22.
- Médecins Sans Frontières (MSF). 2004. *Two Pills a Day Saving Lives: Fixed-Dose Combinations of Antiretroviral Drugs*. MSF Briefing Note. [Online] Available: <http://www.accessmed-msf.org/prod/publications.asp?scntid=16220041418372&contenttype=PARA&> [2005, December 20]
- Médecins Sans Frontières (MSF). 2005. *Action Needed to Tackle the Second Wave of the AIDS Drug Pricing Crisis*. 26 July. [Online] Available: <http://www.accessmed-msf.org/prod/publications.asp?scntid=2672005182505&contenttype=PARA&> [2005, December 20]
- Médecins Sans Frontières (MSF) & Infectious Disease Epidemiology Unit, University of Cape Town (UCT). 2003. *Providing HIV Services Including Antiretroviral Therapy at Primary Health Care Clinics in Resource-Poor Settings: The Experience from Khayelitsha. Activity Report 2003*. Cape Town: MSF.

- Medical Research Council (MRC). 2003. *Initial Estimates from the South African National Burden of Disease Study, 2000*. MRC Policy Brief, No. 1, March 2003. Tygerberg: MRC.
- Mills, A. 2005. Mass Campaigns Versus General Health Services: What Have We Learnt in 40 Years about Vertical Versus Horizontal Approaches? *Bulletin of the World Health Organisation*. 83 (4).
- Ministry of Health (MOH), Malawi. 2003. *Treatment of AIDS. Guidelines for the Use of Antiretroviral Therapy in Malawi*. Lilongwe: Ministry of Health.
- Ministry of Health and Child Welfare (MOHCW), Republic of Zimbabwe. 2003. *Guidelines for Antiretroviral Therapy in Zimbabwe*. Harare: Ministry of Health and Child Welfare.
- Morrell, R. Ed. 2001. *Changing Men in Southern Africa*. London: Zed Books.
- Morris, L. & Cilliers, T. 2005. Viral Structure, Replication, Tropism, Pathogenesis and Natural History. In *HIV/AIDS in South Africa*. Q. Abdool Karim and S.S. Abdool Karim (Eds.). New York: Cambridge University Press. 79-88.
- Mukherjee, J. 2004. Basing Treatment on Rights Rather than Ability to Pay: 3 by 5. *Lancet*. 363:1071-1072.
- Myer, L. & El-Sadr, W. 2004. Expanding Access to Antiretroviral Therapy through the Public Sector – The Challenge of Retaining Patients in Long-Term Primary Care. *South African Medical Journal*. 94(4):273-274.
- Naimak, T. H. 2006. *Antiretroviral Treatment in the Western Cape: A Success Story Facilitated by the Global Fund*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, August 23].
- Natrass, N. 2003. *Highly Active Antiretroviral Therapy and Risky Sex. Is There a Link?* Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, February 23].
- Natrass, N. 2004. *The Moral Economy of AIDS in South Africa*. Cambridge: Cambridge University Press.
- Natrass, N. 2006a. *South Africa's 'Rollout' of Highly Active Antiretroviral Therapy: A Critical Assessment*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, June 5].
- Natrass, N. 2006b. What Determines Cross-Country Access to Antiretroviral Treatment? *Development Policy Review*. 24(3):321-337.
- Natrass, N. 2006c. *AIDS, Science and Governance: The Battle over Antiretroviral Therapy in Post-Apartheid South Africa*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, June 5].

- Nattrass, N. & Geffen, N. 2003. *Providing Antiretroviral Treatment for All Who Need It in South Africa*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, February 23].
- Nattrass, N. & Geffen, N. 2004. *The Impact of Reduced Drug Prices on the Cost-Effectiveness of HAART in South Africa*. Cape Town: Centre for Social Science Research, University of Cape Town. [Online] Available: http://www.cssr.uct.ac.za/asru_pubs.html . [2006, February 23].
- Ncayiyana, D. J. 2004. Antiretroviral Treatment Roll-Out Policy is in Place – Now for the Implementation Challenges. *South African Medical Journal*. 94(2).
- Ndlovu, N. & Daswa, R. 2006a. *Monitoring AIDS Treatment Rollout in South Africa: Lessons from the Joint Civil Society Monitoring Forum (JCSMF)*. Budget Brief No. 161. 13 April. Cape Town: AIDS Budget Unit, IDASA.
- Ndlovu, N. & Daswa, R. 2006b. *Review of Progress and Expenditure on the Comprehensive Plan for HIV and AIDS for South Africa*. Occasional Paper. 23 June. Cape Town: AIDS Budget Unit, IDASA.
- Ntuli, A *et al.* 2003. HIV/AIDS and Health Sector Responses in South Africa -Treatment Access and Equity: Balancing the Act. Health Systems Trust and EQUINET Discussion Paper Number 7, September 2003.
- Opie, L. H. 2005. HIV/AIDS in South Africa. *Lancet*. 366:291.
- Orrell, C *et al.* 2003. Adherence is Not a Barrier to Successful Antiretroviral Therapy in South Africa. *AIDS*. 17:1369–1375.
- Parker, W. *et al.* 2002. *On the Move: The Response of Public Transport Commuters to HIV/AIDS in South Africa*. Johannesburg: Centre for AIDS, Development, Research and Evaluation. [Online] Available: http://www.cadre.org.za/pdf/pdf/On_the_Move_Final_Report.pdf . [2006, January 21].
- Peacock, D. 2005. Urgency and Optimism: Masculinities, Gender Equality and Public Health. *Agenda*. Special Focus 2005, Gender, Culture and Rights: 146-153.
- Peacock, D. & Botha, M. 2004. The New Gender Platforms and Fatherhood. In *Baba? Men and Fatherhood in South Africa*. R. Morrell and L. Richter (Eds.). Pretoria: Human Science Research Council.
- Pienaar, D., Myer, L., Cleary, S., Coetzee, D., Michaels, D., Cloete, K., Schneider, H. & Boulle, A. 2006. *Models of Care for Antiretroviral Service Delivery*. Cape Town: University of Cape Town.
- Population Council. 2001. *Power in Sexual Relationships. An Opening Dialogue among Reproductive Health Professionals*. New York: Population Council.
- Provincial Administration Western Cape, 2004. *Antiretroviral Treatment Protocol*. Cape Town: Department of Health.

- Robins, S. 2004. 'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid. *Journal of Southern African Studies*. 30 (3).
- Rosen, S., Sanne, I., Collier, A. & Simon, J. L. 2004. Hard Choices: Rationing Antiretroviral Therapy for HIV/AIDS in Africa. *Lancet Viewpoint*. [Online] Available: <http://image.thelancet.com/extras/04art3077web.pdf> . [2006, January 23].
- Rosen, S., Sanne, I., Collier, A. & Simon, J. L. 2005. Rationing Antiretroviral Therapy for HIV/AIDS in Africa: Choices and Consequences. *PLoS Medicine*. 2(11):1098-1104.
- Schneider, H. (ed.) 2003. Scaling Up the Use of Antiretrovirals in the Public Health Sector: What are the Challenges? Proceedings of a seminar hosted by the School of Public Health and the Perinatal HIV Research Unit, University of the Witwatersrand, 1 August.
- Schneider, H. & Coetzee, D. 2003. Strengthening the Health Care System and Ensuring Equity in the Wide Scale Implementation of an Antiretroviral Therapy Programme in South Africa'. *South African Medical Journal*. 93(10):772-3.
- Scott, V.E., Chopra, M., Conrad, L. & Ntuli, A. 2005. How Equitable is the Scaling Up of HIV Service Provision in South Africa? *South African Medical Journal*. 95(2):109-113.
- Selikow, T-A., Zulu, B. & Cedras, E. 2002. The Ingagara, the Regte and the Cherry: HIV/AIDS and Youth Culture in Contemporary Urban Townships. *Agenda*. 53:22-32.
- South African Community Epidemiology Network on Drug Use (SACENDU) & Medical Research Council (MRC). 2006. Alcohol and Drug Abuse Trends: July-December 2005 (Phase 19). *SACENDU Update*. 28 June. [Online] Available: <http://www.sahealthinfo.org/admodule/sacendujun2006.pdf> . [2006, August 23].
- Statistics South Africa. 2003. *Census 2001: Census in Brief*. Pretoria: Statistics South Africa.
- Statistics South Africa. 2006. *Mortality and Causes of Death in South Africa, 2003 and 2004. Findings from Death Notification*. Pretoria: Statistics South Africa.
- Stein, J. 2005. The Impact of Antiretroviral Provision on HIV/AIDS Prevention. *AIDS Bulletin*. 14(1).
- Stevenson, M. 2003. HIV-1 Pathogenesis. *Nature Medicine*. 9(7):853-860.
- Stewart, R & Loveday, M. 2005. *Public HAART Projects in South Africa -- Progress to November 2004*. Durban: Health Systems Trust.
- Stewart, R., Padarath, A. & Bamford, L. 2004. *Providing Antiretroviral Treatment in Southern Africa: A Literature Review*. Durban: Health Systems Trust.
- Stillwaggon, E. 2002. HIV/AIDS in Africa: Fertile Terrain. *The Journal of Development Studies*. 38(6): 1-22.

- Stillwaggon, E. 2003. Racial Metaphors: Interpreting Sex and AIDS in Africa. *Development and Change*. 34(5).
- Subedar, H. 2005. The Nursing Profession: Production of Nurses and Proposed Scope of Practice. In *South African Health Review 2005*. Durban: Health Systems Trust.
- Thom, A. 2004. *Western Cape Starts Spending AIDS money*. Centre of the Study of AIDS. [Online] Available: www.csa.za.org/article/articleview/327/1/1/ [2005, December 20]
- Treatment Action Campaign (TAC). 2003. *Treatment Action Campaign (TAC) Report for January 2002 to February 2003*. [Online]. Available: <http://www.tac.org.za/> . [2005, December 20]
- Treatment Action Campaign (TAC). 2004. *Annual Report for 1 March 2003 to 29 February 2004*. [Online]. Available: <http://www.tac.org.za/> . [2005, December 20]
- Treatment Action Campaign (TAC). 2005a. *TAC Annual Report for 1 March 2004 to 28 February 2005*. [Online]. Available: <http://www.tac.org.za/> . [2005, December 20]
- Treatment Action Campaign (TAC). 2005b. National ARV Rollout Statistics. [Online] Available: <http://www.tac.org.za/> . [2005, December 20]
- Treatment Action Campaign (TAC). 2005c. Health Workers Speak Out. *Equal Treatment*. 18. Newsletter of the Treatment Action Campaign.
- Treatment Action Campaign (TAC). 2006a. MSF Clarifies the Organisation is Staying in Khayelitsha. *TAC Electronic Newsletter*. 16 January.
- Treatment Action Campaign (TAC). 2006b. The HIV Epidemic: A Discussion of the Response of the South African Government. Submission to African Peer Review Mechanism. February.
- Treatment Action Campaign (TAC) & AIDS Law Project (ALP). 2003. Traditional Medicines and Traditional Healers in South Africa. Discussion Paper prepared for the Treatment Action Campaign and AIDS Law Project, 27 November 2003. [Online] Available: http://www.tac.org.za/Documents/ResearchPapers/Traditional_Medicine_briefing.pdf [2005, November 15]
- Treatment Action Campaign (TAC) & AIDS Law Project (ALP). 2004. *Updated First Report on the Implementation of the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa*. [Online] Available: <http://www.tac.org.za/Documents/ARVRollout/FinalFirstARVRolloutReport.pdf>. [2005, November 15]

- Treatment Action Campaign (TAC) & AIDS Law Project. 2005. *'Let Them Eat Cake' - A Short Assessment of Provision of Treatment and Care 18 Months After the Adoption of the Operational Plan. Updated Second Joint Report on the Implementation of the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa*. June. [Online] Available: <http://www.tac.org.za/Documents/JCSMF/2ndALP-TACreport.pdf>. [2006, June 15]
- United Nations (UN). 1966. *International Covenant on Economic, Social and Cultural Rights*. [Online] Available: <http://www.ohchr.org/english/law/cescr.htm> [2006, June 21]
- Joint United Nations Programme on HIV/AIDS (UNAIDS). 2005. *AIDS Epidemic Update. December 2005*. Geneva: UNAIDS.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). 2006. *2006 Report on the Global AIDS Epidemic*. Geneva: UNAIDS.
- Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA) & United Nations Development Fund for Women (UNIFEM). 2004. *Women and HIV/AIDS: Confronting the Crisis*. New York: UNAIDS, UNFPA & UNIFEM.
- United Nations Development Programme (UNDP). 2005. *Human Development Report*. [Online]. Available: <http://hdr.undp.org/reports/global/2005/>. [2006, June 12].
- United Nations High Commissioner of Human Rights (UNHCHR). 2004. *Status of Ratifications of the Principal International Human Rights Treaties*. New York: UNHCHR.
- Usdin, S. 2003. *The No-Nonsense Guide to HIV/AIDS*. London: Verso.
- Van Damme, W & Kegels, G. 2006. Health System Strengthening and ART Scaling Up: The Need for Context-Specific ART Delivery Models. Accepted for publication in *Reproductive Health Matters*. Quoted by Kober, K & Van Damme, W. 2006. Expert Patients and AIDS Care. A Literature Review on Expert Patient Programmes in High-Income Countries and an Exploration of their Relevance for HIV/AIDS Care in Low-Income Countries with Severe Human Resource Shortages. Department of Public Health, Institute of Tropical Medicine, Antwerp, March.
- Van der Vliet, V. 2004. South Africa Divided against AIDS: a Crisis of Leadership. In *AIDS and South Africa: The Social Expression of a Pandemic*. K.D. Kaufman & D. L. Lindauer, (Eds.). New York: Palgrave Macmillan. 48-93.
- Van Dyk, A.C. & Van Dyk, P.J. 2003. "What is the Point of Knowing?": Psychosocial Barriers to HIV/AIDS Voluntary, Counselling and Testing Programmes in South Africa. *South African Journal of Psychology*. 33(2):118-125.
- Van Lettow, M., Fawzi, W.W., Semba, R. 2003. Triple Trouble: The Role of Malnutrition in Tuberculosis and Human Immunodeficiency Virus Co-infection. *Nutrition Reviews*. 61(3):81-90.

- Visser, M. 2005. Nutritional Prophylaxis. In *HIV/AIDS in South Africa*. Q. Abdool Karim and S.S. Abdool Karim (Eds.). New York: Cambridge University Press. 463-476.
- Von Schoen Angerer, T., Wilson, D., Ford, N., & Kasper, T. 2001. Access and Activism: The Ethics of Providing Antiretroviral Therapy in Developing Countries. *AIDS*. 15 (5):S81-S90.
- Ware, N. C., Wyatt, M. A. & Tugenberg, T. 2005. Adherence, Stereotyping and Unequal HIV Treatment for Active Users of Illegal Drugs. *Social Science and Medicine*. 61:565-576.
- Wendo, C. 2003. Africans Advocate Antiretroviral Strategy Similar to DOTS. *Lancet*. 362:1210.
- Wood, R. 2005. Antiretroviral Therapy. In *HIV/AIDS in South Africa*. Q. Abdool Karim and S.S. Abdool Karim (Eds.). New York: Cambridge University Press. 504-523.
- World Health Organisation (WHO). 2002. *WHO Traditional Medicine Strategy 2002-2005*. Geneva: WHO.
- World Health Organisation (WHO). 2003. *Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa*. Geneva: WHO.
- World Health Organisation (WHO). 2004a. *Scaling Up Antiretroviral Therapy in Resource-limited Settings: Treatment Guidelines for a Public Health Approach. 2003 Revision*. Geneva: WHO.
- World Health Organisation (WHO). 2004b. *Guidance on Ethics and Equitable Access to HIV Treatment and Care*. Geneva: WHO.
- World Health Organisation (WHO). 2004c. Integrated Management of Adolescent and Adult Illness (IMAI). [Online]. Available: <http://www.who.int/3by5/publications/documents/imai/en/>. [2006, July 15].
- World Health Organisation (WHO). 2005a. *Progress on Global Access to HIV Antiretroviral Therapy, An Update on "3 by 5"*. Geneva: WHO.
- World Health Organisation (WHO). 2005b. *South Africa Summary Country Profile for HIV/AIDS Treatment Scale-Up*. Geneva: WHO.
- World Health Organisation (WHO). 2005c. *Combating TB- The DOTS Strategy*. . [Online] Available: <http://w3.who.org/EN/Section10/Section186/Section190.htm>. [2005, October 16]
- World Health Organisation (WHO). 2006. *Progress on Global Access to HIV Antiretroviral Therapy, A Report on "3 by 5" and Beyond*. Geneva: WHO.

List of Informants

Provincial Department of Health

Dr. Keith Cloete (August 8, 2006): Provincial Director for HIV/AIDS, Sexually Transmitted Infections (STIs) and Tuberculosis (TB) and Acting Chief Director for District Health Services and Programmes.

Dr. Nevilene Slingers (August 9, 2006): Provincial ARV Programme Manager.

Ms. Meg Osler (June 30, 2006): Co-ordinator of the ARV Monitoring and Evaluation Programme of the Provincial Department of Health.

Ms. Luzette Van Nierkerk (July 14, 2006): Assistant Director of the Integrated Nutrition Programme, Comprehensive Health Programmes of the Provincial Department of Health.

City of Cape Town Department of Health

Dr. Ivan Toms (July 13, 2006): Director of Health of the City of Cape Town Department of Health.

Dr. Pren Naidoo (August 7, 2006): Director of HIV/AIDS and TB of the City of Cape Town Department of Health.

Implementing Partners

Dr. Eric Goemaere (July 18, 2006): Head of Mission of Médecins Sans Frontières (Doctors without Borders) in South Africa.

Dr. Ashraf Grimwood (July 10, 2006): Executive Director of Absolute Return for Kids (ARK) in South Africa, an international (U.K.-based) NGO.

Ms. Anita Jason (July 10, 2006): Patient Advocate Programme Manager of Absolute Return for Kids (ARK) in South Africa.

Professor Robin Wood (August 7, 2006): Director of the Desmond Tutu HIV Centre, Institute for Infectious Disease and Molecular Medicine, University of Cape Town and a Professor of Medicine.

Academics/Clinicians

Dr. Gary Maartens (June 29, 2006): Clinical pharmacologist, founder of the adult HIV clinic at Groote Schuur Hospital and lecturer at the University of Cape Town.

Dr. Andrew Boule (July 27, 2006): Researcher at the Infectious Diseases and Epidemiology Unit, University of Cape Town.

Civil Society Partners and ARV Roll-Out Monitoring Organisations

Ms. Sipho Mthathi (July 17, 2006): General Secretary of the Treatment Action Campaign (TAC).

Ms. Fredalene Booyesen (July 20, 2006): Provincial Organizer of the Western Cape Treatment Action Campaign (TAC) Provincial Office.

Ms. Ntombozuko Khwaza (July 20, 2006): Treatment Project Co-ordinator of the Western Cape Treatment Action Campaign (TAC) Provincial Office.

Ms. Fatima Hassan (July 11, 2006): Attorney and former Deputy Head of the AIDS Law Project (ALP) and secretariat of the Joint Civil Society Monitoring Forum (JCSMF).

The Workings of the HIV Retrovirus and Antiretroviral Therapy

In order to understand the enormous impact of ART on individuals' lives and, thus, on the public health system, it is critical to comprehend the workings of the Human Immunodeficiency Virus (HIV) and how ART suppresses it. HIV is a retrovirus that affects the immune system in numerous ways leading to its ultimate disintegration and the on-set of Acquired Immune Deficiency Syndrome (AIDS) (Morris & Cilliers, 2005; Stevenson, 2003). Within the first weeks of infection there is a high level of virus replication that is subsequently followed with a viral load decrease as the immune system begins to respond to the virus (Morris & Cilliers, 2005). As a result, people living with HIV often remain healthy-looking for the first years of infection and it can take on average eight to ten years before the onset of AIDS (*ibid*).

The human immune system operates in a multitude of ways (Stevenson, 2003). It comprises of lymphoid organs, such as tonsils, the spleen and bone marrow, and lymph containing white blood cells that circulate in the body via the lymph vessels and the blood circulation system. These white blood cells include a host of different types of cells, chiefly lymphocytes, of which there are two key types: B cells and T cells. B cells produce antibodies and attach to a foreign invading body (also known as an antigen) to mark it for destruction by other immune cells. T cells can not only mark antigens but can also destroy them and this includes the CD4+ T cells that are in the forefront of HIV/AIDS research of the HIV virus and its pathogenesis. These CD4+ T cells alert B cells to start making antibodies, activate other T cells and immune system scavenger cells called macrophages, and influence which type of antibody is produced. There are also other T cells known as the CD8+ cells that attack and destroy antigen-infected cells. All these lymphocytes circulate the lymph and circulatory systems looking for antigens to protect the host body from. Lymphoid organs serve as nodes of concentrated lymphocyte activity and production.

HIV works by affecting the immune system at many different levels. Firstly, HIV directly infects the body's CD4⁺ T lymphocytes (which is a direct receptor for the virus), leading to a shorter life span of the cell and its ultimate death (Stevenson, 2003). In time, this leads to a complete depletion of one's CD4⁺ cell count greatly compromising the body's immune system and leaving the person extremely vulnerable to opportunistic infections. Typically, ARV protocols dictate that when CD4⁺ cells reach 200 cells/mm³ or below, or if the person is showing health indicators of reaching Stage IV of HIV disease, treatment should begin (WHIO, 2004a). (Figure 17 below depicts HIV disease progression including CD4⁺ cells counts with the on-set of ART).

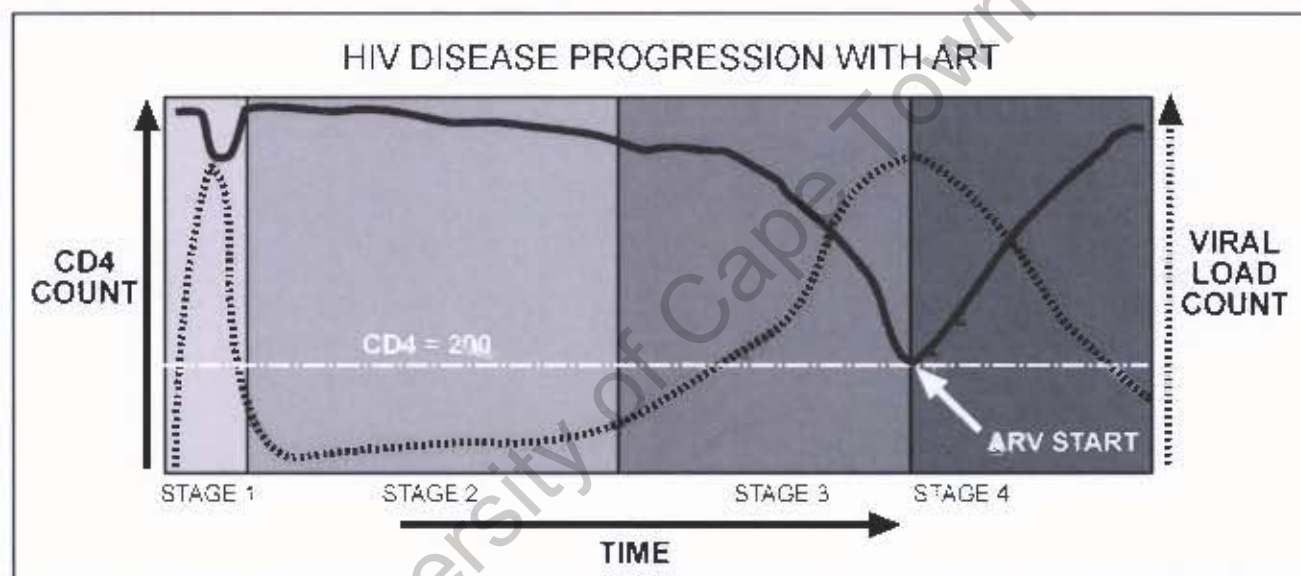


Figure 17 : HIV DISEASE PROGRESSION WITH ART (ARK, 2005)

Further, HIV infects T cells along their full life cycle: Not only does it infect activated T cells but also those that are in a resting state as well as those that are quiescent (Stevenson, 2003). Secondly, the HIV virus also targets and infects antigen-presenting cells, namely macrophages and dendritic cells. Infection of macrophages occurs mainly through the CCR5 co-receptor and although infected T cells greatly outnumber infected macrophages in HIV infected individuals, the infected macrophage contributes to provirus production at great rates particularly by enhancing further viral dissemination to CD4⁺ T cells (*ibid*). Infected dendritic cells have shown to have a similar characteristic, sending signals to T cells that increase their replication of the provirus (*ibid*). Finally, observations have shown that both infected and uninfected cells are adversely affected by HIV leading to greater atrophy of the immune system's "fighter" cells (*ibid*).

There are currently no cures or reliable vaccines for HIV and AIDS. Without ART, the life expectancy of someone living with HIV/AIDS is drastically reduced (Farmer *et al.*, 2001; Schneider & Coetzee, 2003; Coetzee *et al.*, 2004a). ART works to halt the escalating effects of HIV viral replication on the various cells comprising the human immune system. *Figure 18* below pictorially depicts this important and life-saving process. As such, the advent of ART has effectively transformed HIV/AIDS from a terminal disease into the realm of chronic illness.

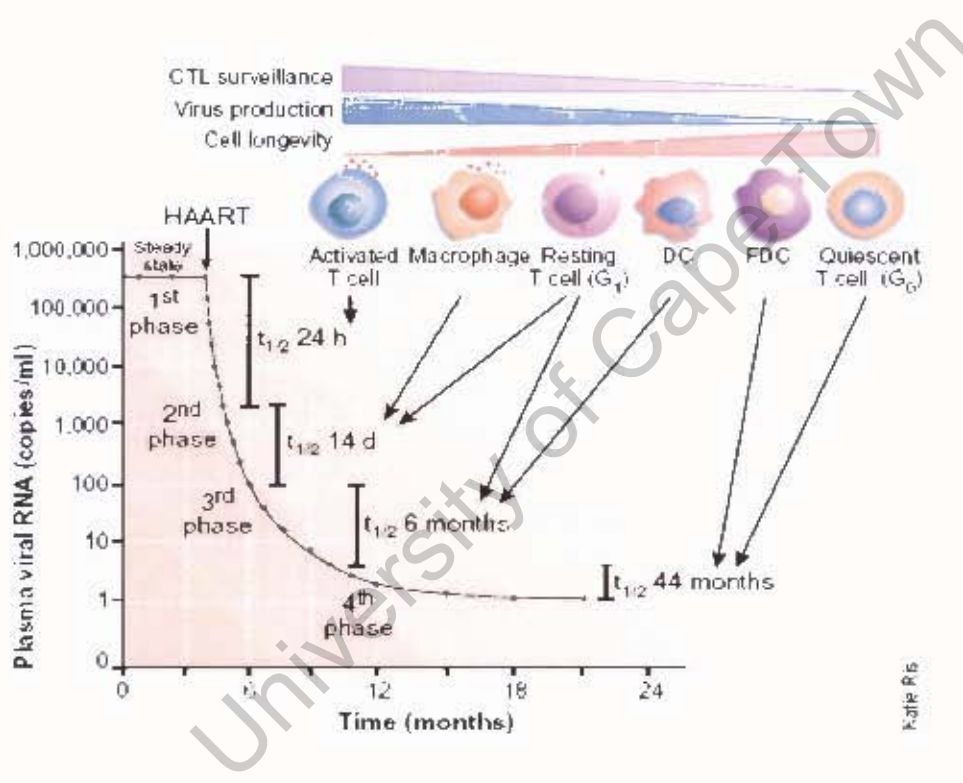


Figure 18 : AN OVERVIEW OF HIV VIRAL RESERVOIRS WITH THE ON-SET OF THE USE OF ART AND THE EFFECT ON VARIOUS IMMUNE CELLS (STEVENSON, 2003)

List of ARV Sites in the Western Cape Province and People on ART, June 2006

	New	Adults	Children	All	Total	Adults	Children	All
Academic Complex								
Groote Schuur Hospital	19	9	28	437	306	743		
Red Cross Hospital	0	22	22	0	339	339		
Tygerberg Hospital	36	18	54	823	330	1,153		
Subtotal	55	49	104	1,260	975	2,235		
Boland Overberg								
Ceres Hospital	8	0	8	116	11	127		
Frans Danges Hospital	20	4	24	398	51	449		
Grabouw	11	0	11	105	17	122		
Hermanus	10	0	10	171	12	183		
Robertson	15	0	15	160	4	164		
Swellendam	6	0	6	30	4	34		
Subtotal	70	4	74	980	99	1,079		
Metro District Health Services								
Crossroads	44	1	45	600	59	659		
Delft	34	0	34	292	0	292		
Eersterivier	12	0	12	155	0	155		
False Bay Hospital	11	0	11	63	1	64		
Guguletu CHC	85	5	90	1,477	132	1,609		
Hout Bay Clinic	9	0	9	337	11	348		
Ikhwezi Clinic	17	0	17	129	0	129		
Kraaifontein	47	3	50	592	19	611		
Langa Clinic	31	0	31	704	55	759		
Masiphumelele CHC	29	1	30	408	21	427		
Michael M CHC	72	8	80	1,434	88	1,522		
Michels Plain CHC	54	4	58	1,029	9	1,038		
Nolungile CHC	67	7	74	1,000	95	1,095		
Retroat CHC	0	0	0	18	0	18		
Robbie Nurrock	20	0	20	482	1	493		
Site B, Khayelitsha CHC	81	7	88	1,553	130	1,683		
Sonneset Hospital	8	1	9	14	0	20		
Tableview	35	2	37	375	6	380		
Westmeur Hospital	4	0	4	99	4	103		
Subtotal	660	39	699	10,819	646	11,465		
Metro Institutions								
G.F. Jooste Hospital	26	0	26	520	0	520		
Hottentots Holland Hospital	20	0	21	358	45	403		
Victoria Hospital	10	2	12	365	53	418		
Subtotal	56	3	59	1,243	98	1,341		
South Cape / Karoo								
Beaufort West Hospital	6	0	6	88	20	114		
George Hospital	15	6	21	372	71	393		
Krystna	20	0	20	309	23	332		
Mosselbaai	11	2	13	211	14	225		
Oudtshoorn	6	0	6	112	15	127		
Plettenberg CHC	16	3	19	111	10	121		
Prins-Albert CHC	1	0	1	21	1	22		
Theribaletu CHC	5	0	5	68	0	68		
Subtotal	80	11	91	1,242	160	1,402		
West Coast Winelands								
Citrusdal Hospital	5	0	5	33	1	34		
Cloetesville DII	14	1	15	275	28	303		
Malmesbury Hospital	10	0	10	150	16	166		
TC Newnham Hospital	31	8	39	581	153	734		
Vredenberg	7	0	7	103	8	111		
Vredendal	2	0	3	63	8	71		
Subtotal	69	10	79	1,205	214	1,419		
Grand Total	990	116	1,106	16,749	2,192	18,941		