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Human rights discourses around the provision of antiretroviral drugs to HIV positive pregnant women in South Africa: implications for social work

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CHAPTER ONE
INTRODUCTION

This chapter outlines the rationale of the study, provides a problem statement, explains its aims, explicates the underlying assumptions and theoretical paradigm, and discusses the anticipated value of the study. An overview of the chapters that will follow is also provided.

1.1 RATIONALE OF THE STUDY

Today South Africa faces the biggest health threat in its history - the HIV/AIDS epidemic. Currently, there are around six million HIV infected persons in the country with 1,800 new infections each day (www.hivaids.co.za, 2004). Unless adequate measures are taken, the epidemic will continue to adversely affect many more people. This being the fact, the South African government's response has to date been slow. As a result, government has been accused of refusing, or deliberately delaying, to rollout antiretroviral drugs (ARVs) to those who need but cannot afford them. One particularly vulnerable group in this context are HIV positive pregnant women giving birth in public health care facilities and their newborn babies. Over the past few years, much of the public debate on the issue of ARVs has centered on this sub group. In the course of this prolonged debate, it has been claimed by NGOs and other civil society structures that the lack of government action has violated court ruling and basic human rights principles.

Social Work as a profession has since its inception been concerned with the plight of marginalized persons, groups and communities. Some strands in Social Work have focused on assisting client systems in making adjustments to the demands posed by broader society on their social functioning - without much critical reflection. Other strands, however, have defined the purpose of Social Work as deriving "from its solidarity with the various marginalized groups in society, that is those

who are subject to structural injustices" (Hölscher, 2001:42). For example, the advocacy role and social action approach that Social Work has since assumed in various contexts stands in the tradition of the latter strands. Therefore, a situation as the one described above - where there is serious concern that government action might be in violation of the human rights of a group of people who are particularly vulnerable due to, *inter alia*, their health status - calls on Social Work to take a position and, if need be, to help defend the rights of its client systems.

The research is directed at reviewing the history of human rights as an institution and a discourse, placing this in the South African context and by doing so, enabling a critical reflection of the arguments put for and against the use of ARVs in HIV positive pregnant women. The problem this study seeks to investigate is therefore whether or not HIV positive pregnant women have a human right to accessing ARV treatment on giving birth, and if they do, how such a right might be enforced. The researcher believes that only when fully understanding the complexities surrounding the application of human rights in specific contexts, can Social Work fulfill its advocacy mandate adequately.

1.2 AIMS OF THE STUDY

The research presented in the following sought to explore some of the key positions within the South African government and the civil society sector on the health rights of HIV positive pregnant women, and how these different positions have evolved in response to each other. Of specific concern was the question of how human rights discourses have been employed in this regard. The researcher further pursued the question of what the implications of these debates are for the Social Work profession in South Africa. In view of these guiding questions, the following research aim and sub aims were formulated.

1.2.1 MAJOR AIM

The major aim of the study was to explore how discourses of human rights are employed in the debate around the comprehensive provision of ARVs to HIV positive pregnant women and how these impact Social Work in South Africa.

1.2.2 SUB AIMS

The major aim of the study was achieved by attaining the following sub aims:

- To review relevant facts and socio-medical history of HIV/AIDS;

- To review the conceptual and institutional history of human rights, specifically the socio-economic right to health, and the way human rights discourses have been employed in various contexts with a view to interpreting and realising the right to health;

- To review the different perspectives that have contributed to the public debate on the provision of ARVs to HIV positive pregnant women in South Africa in the period 1999 to 2004;

- To explore some of the key positions that have been articulated from within the South African government and the NGO sector on the human, specifically health, rights of HIV positive pregnant women; and

- To develop, in view of this background, a Social Work perspective on the human rights of HIV positive pregnant women in South Africa, thereby contributing to the development of the profession's value base and body of knowledge in response to locally specific challenges.

1.3 UNDERLYING ASSUMPTIONS OF THE STUDY

The following assumptions have informed the overall research:

- Social Work as a profession needs to be based on a human rights foundation as it has an ethical obligation to defend and promote the human rights of marginalized groups in society;

- HIV positive pregnant women and their newborn babies are such a marginalised group, thus forming a particular client population in Social Work;

- The arguments presented by the South African government against the provision of ARVs to HIV positive pregnant women may not reflect the entirety of its reasons;

- There is a legal and moral obligation for government to provide ARVs to HIV positive pregnant women on giving birth;

- The interpretation and realisation of human rights is subject to economic, political and power interests; and

- Therefore, exact meanings of human rights are contested in as much as they can be used as a tool in societal power struggles.

1.4 THEORETICAL PARADIGM UNDERLYING THE STUDY

This study was aimed to generate understanding around a particular discourse and how it is employed in a specific policy context, which was done specifically from a human rights perspective. Its rationale, intentions and underlying assumptions imply that the study was rooted in the researcher's concern about the possibility of human rights violations against a particularly vulnerable group in South African society, that is,

HIV positive pregnant women and their newborn babies. It was also rooted in the researcher's understanding of the nature of Social Work, that is, a profession which generates its moral and ethical legitimacy from its alignment with broader human rights and social justice objectives.

This places the study within a theoretical paradigm, which has been referred to by Eagle, Hayes and Sibanda (1999) as *standpoint methodologies*. Within this frame of reference, accepted qualitative, and quantitative, methodologies with regard to sampling, data collection and analysis are directed towards identifying and challenging vested power interests, and become a moral and political undertaking (ibid.). The implication of this is that the study presented here did not intend to be neutral. Eagle, Hayes and Sibanda (1999:439) write that standpoint research rather than being a methodology or set of methodologies, "should be viewed as positions, allegiances or standpoints which researchers may embrace in conducting research". Standpoint research "seeks to give voice to the concerns of [marginalized groups in society] and to broaden the scope of research" (ibid.).

Standpoint methodologists are therefore critical both of positivist and more conventional interpretive approaches. With regard to the latter, it is claimed that they "are not going far enough in incorporating a commitment to a set of emancipatory values in undertaking research" (ibid.). Instead, there are three dimensions that appear to be common to all standpoint research. There is firstly, a critique of ideology as "the production and dissemination of believes or values that … confer power on dominant groups to control and exploit others" (Walby in ibid, 440). Secondly, there is a principal commitment to the interests of oppressed and marginalized population groups. Therefore, finally, standpoint methodologies are generally aimed at contributing to actual change in societal relations and practices, to these groups' benefit.

In other words, this study was undertaken with a particular socio-political purpose. Care has to therefore be taken that while it needs to be as methodologically sound as any other study, at least two additional responsibilities have to be met. These are, being transparent and making the purpose explicit, and contributing to contemporary public discourse and debate on the subject matter, respectively.

1.5 ANTICIPATED VALUE OF THE STUDY

The debate around the provision of antiretroviral drugs to HIV positive pregnant women in South Africa is a topic which has, according to the researcher's point of view, not yet been adequately explored by the social sciences, especially from a human rights perspective. In addition, the HIV/AIDS epidemic is threatening the post-apartheid government's reconstruction and development programme, yet its response has been said to be slow in treating its HIV positive citizens with antiretroviral drugs. This in turn has implications for Social Work practice, both in terms of service rendering to a particular client group, and in terms of the more general question of how Social Work can contribute better to the realization of the human rights of its client systems at large.

With this in mind, it is hoped that the research would firstly help to improve awareness of the constitutional rights of people in general and those living with the virus in particular. Secondly, by offering a deeper insight into the dynamics of the subject matter, the study might be able to serve as a background document for further research that could ultimately lead to drafting a sound policy on the supply of antiretrovirals. It would thereby contribute to the existing stock of knowledge and literature on the use of these drugs from a human rights, and a Social Work angle. This would in turn contribute to the strengthening of social justice and human rights discourses within the Social Work profession, and amongst broader civil society structures in the field of HIV/AIDS. It is believed that knowledge of human rights - generally and applied to the specific context of HIV/AIDS in South Africa - would help enhance the

abilities of both Social Work educators and practitioners in relation to their policy advocacy role.

1.6 OUTLINE OF CHAPTERS

The first chapter has provided the introductory arguments regarding the study's rationale, problem statement, the aims, underlying assumptions, theoretical paradigm and its anticipated value of the study. Chapter Two contains methodological considerations. It details the data collection and sampling process, research tool, approach to data analysis, ethical considerations as well as the study's limitations.

Chapter Three deals with HIV/AIDS' historical background and its development, the different modes of transmission, its present scale as well as the various historical, economic, socio-cultural and political factors that have contributed to the epidemic's high prevalence in South Africa. The conclusion reached in this chapter is that although there is no total cure to the epidemic so far, antiretroviral drugs (ARVs) could however effectively reduce the viral load and prevent mother-to-child transmission (MTCT) of the virus, a scientific finding which has been disputed by some government authorities in South Africa and the so-called 'AIDS dissident' scientists.

In Chapter Four, the conceptual development and relevance of human rights in protecting and promoting people's right to health will be discussed. This will be done by highlighting a number of pertinent human rights materials and the role civil society organizations play in this regard. Emphasis is placed on international human rights statutes with regard to their responses to health rights, especially to the HIV/AIDS epidemic. This chapter concludes by highlighting the universality, interrelatedness and indivisible nature of different civil, political and socio-economic rights. However, it is found that the current global context of neoliberalism has adversely impacted the realization of socio-economic rights especially in the so-called 'Third World /

Developing Countries'. In the South African context, this is exemplified in the GEAR macro-economic strategy that was adopted by the government in 1997

Chapter Five, using the situation of HIV positive pregnant women giving birth in South African health facilities as a case in point, discusses the concept of public health in relation to human rights and Social Work in promoting people's wellbeing. It is found that public health policy, the concept of human rights and the Social Work profession complement each other well in endeavours to promote people's access to health care services. With respect to Social Work, it is evidenced that the profession can play a significant role in transforming existing power relations in the interest of disadvantaged groups in society. In so doing, this chapter concludes by making reference to Social Work approaches such as advocacy, empowerment and social action.

Chapter Six explores the position of different stakeholders (from government and organs outside of government) with regard to the supply of ARVs to HIV positive pregnant women. In addition, the various human rights instruments, court cases and other strategies that were employed by activist groups, and which ultimately led to government's apparent shift in position with regard to ARV provision, are debated. It is found that the lengthy delay to rollout ARVs in the public health sector has been a result of government's use of its political power to distort notions of human rights.

Chapter Seven presents and analyses the gathered data against the reviewed literature. It focuses on barriers in implementing a national ARV rollout programme for the benefit of HIV positive pregnant women giving birth in public health facilities, the provision of ARVs in the context of the current global market economy, implications thereof for inequality in South Africa, the role of human rights discourses in the context of the said debate, and lastly, factors which have led the government to shift its long held position against the said ARV rollout programme.

The study's final chapter summarizes the foregoing chapters and draws conclusion based on the findings from the literature review and the data analysis. Finally, recommendations are made towards, *inter alia,* the need for the South African government to adhere to the values enshrined in the country's Constitution; to work closely and transparently with different organs of civil society; and simultaneously implement the said ARV rollout program while building and strengthening its infrastructural capacity. The various roles Social Work could, and should, assume with regards to improving the human rights of HIV positive pregnant women are also highlighted.

CHAPTER TWO
RESEARCH DESIGN AND METHODOLOGY

The chapter below presents the research design as well as the specific methodologies that were employed in conducting the study, viz. data collection and sampling, research tool, and analysis. Thereafter, ethical considerations and the limitations of the study will be explicated.

Research designs are plans that guide "the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose with economy in procedure" (Sellitz, Johada, Deutsch and Cook, in Terre Blanche and Durrheim, 1999:29). The study aims to generate understanding around a particular discourse[1] and how it is employed in a specific policy context. This will be done from a specific human rights perspective. These prerequisite considerations have had implications both for the overall design and the particular methodologies employed in this study.

First of all, the object of the study was a social artifact, that is, human rights discourses around the provision of ARVs. These discourses have been employed, as pointed out above, by different groups contesting power relations in society. Since such discourses can be traced both in written material and in conversation, written publications and personal interviews were equally important sources of raw data. This fact informed, in turn, the requirements of the sample, the sampling procedure, the choice and development of research tool, as well as the data analysis.

Rather than seeking a sample representative of a particular *population*, care was taken to arrive at a sample representing broad categories of *views* on the subject matter, and representing certain *interests* in the

[1] discourses are practices that systematically form the objects of which they speak (Foucault, in Terreblanche, C. and Durrheim, K. 1999:160)

said power contest. Thus, the sample needed to represent organizations with divergent positions, and individual participants needed to be selected on the merit of their competence in the discourses concerned.

The researcher's interest in deepening his insight into these discourses was guided by themes that had emerged during the preliminary literature study at proposal stage already. This called for a certain level of structure in the research tool. Yet, due the nature of discourse, space had to be created for research participants to explore, elaborate, expand and change themes according to their own perceptions of the subject matter. In other words, the research tool had to be flexible as well.

Finally, in view of the subject matter, it seemed more important to critically engage with *the merits* of different views rather than to investigate, for example, *how many* persons or groups subscribed to these views. Such views, then, needed to be presented, compared, related and critically discussed. Rather than aspiring to arrive at generalisable findings, therefore, a method of data analysis needed to be employed that would ensure findings that had the necessary richness and depth. For these reasons, a qualitative design appeared to be the most useful choice.

2.1 DATA COLLECTION AND SAMPLING PORCESS

An archival research as well as five individual interviews formed the main sources of data. International and South African literature including books, journals, government documents, court judgments, the web site of different NGOs as well as government was reviewed. The literature review helped to explore the history of the issue under discussion by showing its origins and subsequent developments. This archival research was complemented by a limited empirical research, in the course of which interviews were conducted with a selected number of interviewees from relevant organisations.

As far as the review of policy materials are concerned, it needs to be pointed out that there was no coherent and homogenous position at national/provincial levels of government with regard to the provision of ARVs for HIV positive pregnant women. Materials available for review included the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa of 19 November 2003; the Comprehensive five-year HIV/AIDS and STI Strategy that addresses prevention, treatment and care, research and human rights aspects which was adopted in 2000; two more recent documents - the Cabinet statements/speeches (on HIV/AIDS prevention and treatment) of April 17 2002 and October 2002, which have further detailed the preceding policy documents; and the National HIV and AIDS Programme of 19 March 2003. To these were added the various press releases by different key authorities within government.

In order to gather the relevant data, a purposive sample was used. This type of sampling was based on the judgment of the researcher, in that a sample was composed of elements that contain the most characteristic, representative/typical attributes of the population (Singleton et al. cited in de Vos, 2000:198). Thus, a sample of informants was selected from health/AIDS organizations, government departments, and research units that work in areas of lobbying and advocacy.

The following institutions were approached in the sampling process. Interviews were conducted with one representative from each of the following:

- The Treatment Action Campaign (TAC),
- The Wits School of Law: Aids Law Project (WALP),
- The National Department of Health,
- The Gauteng Provincial Department of Health,
- The Chris Hani Baragwanath Hospital - Perinatal HIV Research Unit.

These organizations identified potential participants on the basis of their knowledge in the research area, including policy, legal and medical issues, as well as their ability to adequately represent the organiztion's positions. None of the respondents thus identified were social workers, even though several of them had experience in the use of strategies relevant to Social Work practice. Apart from their prominence and active involvement in the issue, the organizations' proximity - being based in Johannesburg - was a sampling criterion which served to solve the study's time constraint and resource limitation. In other words, there was an element of convenience sampling which informed the research process.

2.2 RESEARCH TOOL

In view of the qualitative nature of the study, semi-structured interviews with guidelines were conducted with the key informants. This method provided for systematic collection of data. At the same time, it facilitated the clarification and elaboration on the answers given as it allowed the interviewer latitude in probing and thus, to enter into a dialogue with the interviewees. Moreover, it allowed interviewees to answer more on their own terms than the standardized interview permits (May, 1997:111).

The chosen interview strategy has a further advantage of providing valuable information owing to the informant's position within the organisation (Marshall & Rossman, 1995:83). The interview guides were structured according to tentative themes that had emerged from a preliminary literature review at the proposal stage of the study. The questions were open-ended so as to allow the informants, according to Marshall and Rossman (1995:84), to express their opinion, use their knowledge and information in answering the questions. The interviews took about 50 minutes each and involved the use of a tape recorder. After the interviews were recorded, a verbatim transcript was done for analysis. The interviews were *formal*- in that a specific time frame was set for the interview.

2.3 DATA ANALYSIS

After the relevant literature was reviewed and interviews were conducted, the empirical data was analysed qualitatively. The analysis was done *manually* because of the small sample size. According to Poggenpoel, in de Vos (1998:337), there is no right or wrong approach to data analysis in qualitative research. However, for the purpose of this research the data was analysed using the "*coding* procedure, that represents the operations by which data are broken down, conceptualised, and put back together" (de Vos, 1998:271). It is further elaborated that there are three steps in coding, one of which is *open coding*. This is the process of breaking down, examining, comparing, conceptualising and categorising data. This step forms the beginning of analysing the tape-recorded and transcribed data followed by *axial coding*. During this phase, connections are made between categories. The data is finally analysed for a third time using *selective coding* whereby systematic relations are made between different categories, validating them and filling those that need further refinement and development (ibid, 1998:271).

Data was critically discussed against each other, and against the findings from the literature review. The result was a refinement, elaboration and adaptation of the themes identified in the literature review. This enabled the researcher to draw conclusions and make recommendations not only regarding the themes discussed with the respondents, but also regarding their implications for Social Work theory, research and practice.

2.4 ETHICAL CONSIDERATIONS

In gathering the data, interviewees were briefed on various ethical considerations. As is attached in appendix III, they were given an information sheet informing them about the objective of the study, the voluntary nature of their participation as well as measures to ensure

confidentiality in the study. The participants of the study were further informed that a copy of the research report would be made available on request. Moreover, they were informed of the availability of counseling service and were given the contact details of the researcher should the need for follow up arise. Last but not least, all sources of information have been duly acknowledged.

Given the theoretical framework of the study, that is the importance attributed to the researcher's standpoint, and his intention to impact back on the investigated discourse and societal structures, it becomes an ethical obligation to seek to publish relevant sections of the study. This would help to ensure that the study unfolds its anticipated value, that is, firstly, to inform - even if indirectly - policy processes around antiretroviral drugs for vulnerable members of South African society. Secondly, to contribute, strengthen and support claims for the realization of human rights, and thirdly, to contribute to the development of locally specific skills, knowledge and values base for Social Work in South Africa.

2.5 LIMITATIONS OF THE STUDY

There are several limitations to this study. Firstly, the research was conducted on a current topic. As the researcher conducted his literature review and his data analysis, the public discourse continued, and changed, and policy decisions were taken and implemented (or not). In addition, the research focused on the rollout of ARVs to HIV positive pregnant women giving birth in public health care facilities. Yet, the question of whether they have a human right to such a rollout, was embedded in a broader discourse around the general provision of the drugs, and the various socio-economic aspects thereof. This shifting and changing subject matter, together with the blurring of its boundaries made it at times difficult to focus the study, and to draw appropriate conclusions.

It appears that the contemporary and contested nature of the topic led to a limitation in the research process: There was a major sense of reluctance on the part of officials from the Department of Health to answer my research questions, never mind answer on time. Despite many telephone and e-mail requests to key authorities at the Department, the researcher was for months unsuccessful in getting hold of them and obtaining any feedback, be it positive or negative. When participation was eventually secured, only a written interview was granted (National Department of Health), and the answers were very limited in scope (both National and Gauteng Departments of Health), making the intended dialogical engagement impossible.

Although recently government promised to adopt a homogeneous position on the wider provision of ARVs to HIV positive pregnant women, there has been for a long time different positions within it. This impacted on the researcher's ability to access all relevant positions that have been held within the South African government. Therefore, only those positions that were accessible, were dealt with, which posed another limitation.

The purposive sampling technique, which was used for collecting data in this study, was a methodological limitation, as only selected interviewees were interviewed. As a result, the findings were constrained in that the input from respondents was not representative of the entire spectrum of possible opinions from the relevant organisations. A further limitation of the sampling technique was that the people who were spoken about and acknowledged to have been marginalized (that is HIV positive pregnant women) did not get a voice. Moreover, although the objective of the research was to develop a Social Work perspective on the human rights of HIV positive pregnant women, social workers have not been interviewed. However, a perspective could be developed, based on the findings that human rights discourses are indeed powerful tools in power struggles, as are the employment of conscientisation, empowerment,

social action, advocacy approaches that have been used in the struggle for the provision of ARVs.

To these was added the researcher's own perceptions which unavoidably influenced the way in which interpretations were made. At the same time, in view of the chosen theoretical paradigm, this does not necessarily need to be viewed negatively. In fact, it may be regarded as the study's particular strength. Rather than seeking to attain a positivist notion of objectivity, the researcher declared his intentions. This kind of transparency was employed to enable readers to develop their own standpoint in relation to the researcher's points of view, thus continuing the critical discourse that formed the subject matter of the study. In addition, such methodological biases were minimised by using a data analysis technique which incorporated/reviewed available literature on the issue beyond the respondents' particular viewpoints.

CHAPTER THREE
HIV/AIDS: A GENERAL OVERVIEW

This chapter deals with HIV/AIDS' historical development, its different modes of transmission, its present scale globally and in South Africa as well as the various historical, socio-economic, cultural and political factors that have contributed to its high prevalence in South Africa. It will be found that although there is no total cure for the epidemic, however, the different versions of ARVs could prevent the transmission of HIV from a pregnant mother to her offspring (both pre- and post-natally). Generally, the ability of ARVs in effectively reducing the viral load in HIV infected victims, media campaign, education, awareness campaign, etc. will also be highlighted.

3.1 HIV/AIDS: ITS HISTORY AND MODES OF TRANSMISSION

In the early 1980s there was an occurrence of unexplained deaths in America especially among homosexual men between 20 and 40 years of age who had previously been all healthy. This strange occurrence became a concern for health professionals and for those in the research field. Most deaths were attributed to a rare form of pneumonia caused by a parasite called Pneumocystis Caranii. Around the same period, in Central Africa, health workers discovered a new disease, which caused severe weight loss and diarrhea which was then called 'slim disease'. The root cause of these symptoms was found to be an immune deficiency (Evian, 1993). By 1983 the virus that causes AIDS had been identified by a French scientist, Luc Montagnier. Shortly thereafter, Robert Gallo, an American scientist, also discovered the virus. It was named the Human Immunodeficiency Virus or HIV (Whiteside and Sunter, 2000:2). It was still unclear where the virus came from, or why it appeared. There is evidence that the virus has been around for at least 20 years. In its embryonic stage the epidemic was referred to as a

disease of the rich, confined to the Western industrialized countries. However, more than ten years after HIV was first described, millions of people were infected worldwide, and by the early 1990s, AIDS has become one of the world's most serious public heath problems (Evian, 1993). The present scale of the epidemic outstrips that of a decade ago. Global estimates of the total number of people living with HIV and AIDS as of end 2003 was reported 37.8 million (www.unaids.org, 2004). According to a 2004 report on the global AIDS epidemic published by UNAIDS, Sub-Saharan Africa remains by far the region worst affected by the epidemic. With just over 10% of the world's population, the region is home to two-thirds of all people living with HIV (ibid).

AIDS is a sexually transmitted disease (STD) that is caused by HIV. Like all viruses HIV is a parasite. Once it enters a person's bloodstream it damages that person's immune system that helps the person in resisting diseases. According to Whiteside and Sunter (2000:7-8), HIV attacks a particular set of cells in the human immune system called CD4 cells which organise the body's overall immune response to foreign bodies and infections that are HIV's prime targets. HIV also attacks immune cells called Macrophages which engulf foreign invaders and ensure that the body's immune system will recognize such invaders in future. Once the virus has attached itself to the cell's surface, it penetrates the wall. Thereafter, it is safe from the body's immune system and cannot be destroyed by the body's defense mechanisms. As a result of this, the body's defense against other infections is weakened which makes the victim vulnerable to opportunistic infections like tuberculosis, pneumonia, etc.

As far as the different modes of transmission of HIV from an infected person to another are concerned, there are various forms. The virus is mostly found in infected people's blood, sperm/vaginal secretions, and breast milk. It can be passed on in these fluids from an infected person to another during unsafe/unprotected sexual intercourse, contact with infected blood, as well as through mother to child transmission (MTCT),

that is pregnancy, childbirth, and breastfeeding. The predominant mode of transmission worldwide, both among homo and heterosexuals is via unprotected *sexual intercourse.* The infection therefore falls within the category of sexually transmitted diseases (STDs). The presence of other STDs (eg. gonorrhea, syphilis, etc) during sexual intercourse and the nature of the intercourse (anal, oral, vaginal) also impact the size of the risk. It is reported that heterosexuals are more likely to be infected by the virus due to the exposure of the vaginal anatomy during intercourse.

Contact with infected blood is another means of transmission of the virus. Whiteside and Sunter (2000:13), note that the use of contaminated blood/blood products is also a dominant way of transmitting the virus, as this creates the chance for the virus to enter directly into the bloodstream. That is why many haemophiliacs were infected when the epidemic was in its initial stage, as the blood donated to them was not screened. Besides blood transfusion, HIV is transmitted, among other things, by the sharing of needles among drug users, tattooing, blades, toothbrushes, etc once they are used by HIV infected people.

Another mode of transmission of the virus is through *Mother to Child Transmission (MTCT)*, which happens pre-natally (during pregnancy), at the time of delivery, or post-natally through breastfeeding. According to a report published by Population Reference Bureau (PRB) (2000:13), more than a million children are living with HIV/AIDS around the world, and more than 4 million have died since the outbreak of the epidemic. Several studies in Africa have shown that those HIV negative infants born to HIV positive mothers later tested positive when their mothers continued to breast-feed them (www.polity.org.za, 2001). In South Africa during 1999 alone, over 60,000 babies were estimated to have contracted HIV through MTCT (Treatment Action Campaign, 2001:5). "The risk of MTCT is influenced partly by the viral load[2] of the mother at

[2] A measure of the amount of HIV in a person's blood (Barrett-Grant et al, 2001:468).

birth - the higher the load the higher the risk. A low CD4 cell count[3] is also associated with increased risk. Antiretroviral drugs may decrease the viral load and may inhibit viral reproduction in the infant, thus decreasing the risk of MTCT" (Whiteside and Sunter 2000:12). Azidothymidine (AZT), an ARV drug, is reported to reduce the risk of passing HIV from mother to child by up to 60%, if taken correctly (University of the Witwatersrand, 2000:3). Furthermore, avoiding breastfeeding and replacing vaginal deliveries by caesarean section can significantly lower the risk. Both these options are difficult to carry out in most Third World countries. The former option that is avoiding breastfeeding by alternative infant feeding options such as bottle-feed is not affordable to the poor. The later option, that is, caesarean section is difficult for women who give birth at home with the aid of midwives and/or in small health centers that do not have the necessary equipments and infrastructure.

3.2 PREVENTION, TREATMENT AND CURE

Ever since the discovery of the HIV virus, many attempts have been made to find remedy that could combat the virus. All these attempts failed and the number of people dying of the infection has since grown every year, especially in Third World countries. To date no cure exists for the disease. The alternative thus left for medical professionals is to develop medicines that would at least reduce the rate of reproduction of the virus once it enters the human body and that would strengthen the body's immune system. Such drugs currently under investigation fall broadly into two groups: immuno-modulators and anti-virals. Immuno-modulators are drugs which reverse the damage done to the immune system in by AIDS. Used on their own, these immune-boosting agents have had disappointing results but they may be useful when combined with antiretroviral drugs (Miller, cited in Craig, 1991:18). Antiretroviral

[3] A measure of white blood cells to find out how seriously a person's immune system has been damaged by HIV – in other words, a measure of how strong a person's immune system is. If you have a CD4 cell count of less than 200, you are classified as 'having developed AIDS' (Barrett-Grant et al, 2001:453).

drugs are aimed at intervening in the life cycle of HIV, preventing it from infecting cells, replicating or getting out of the cell again, so as to maintain the health of people with AIDS. The different versions of AZT and Nevirapine referred to as antiretroviral drugs (ARVs) are among the many drugs developed so far. Whiteside and Sunter (2000:21), state that such developments have resulted in a significant decline in the mortality rates from HIV in the developed world. Clinical studies have shown that AZT can improve the general condition of patients with AIDS or AIDS-related conditions. These patients often gain weight, have a rise in their CD4 cell count and have fewer opportunistic infections (Evian, 1993). Subsequent trials in Africa, using ARVs such as Nevirapine, have also yielded encouraging results. More recently, trials carried out in Johannesburg- the results of which were released to the public at the XIII International AIDS Conference held in Durban in July 2000, indicate comparable/encouraging results using very short courses of Nevirapine alone, with the added benefit of substantially reduced drug costs and complexity of administration (Gray et al, 2000 cited in Law, Democracy and Development, 2002:164).

There are three stages in the treatment of HIV positive people. “The first is when they are infected, but CD4 cell counts are high. At this point, the emphasis is on positive living- staying healthy, eating the correct food and so on. The second stage is when the CD4 cell count begins to drop. At this stage, prophylatic treatment to prevent TB and other common diseases is normally begun. The third stage is the use of antiretroviral drugs to fight HIV directly. This can start when the CD4 cell count drops below 350” (Whiteside and Sunter, 2000:21). Since the first ARVs were developed, many new generations of drugs have become available. At the moment ARVs may be used in single (just one drug), double (a combination of two drugs), triple (three drugs) and HAART[4] (Highly Active Antiretroviral Therapy). HAART is any antiretroviral regimen capable of suppressing HIV for many months and perhaps years in a

[4] another name for anti-retroviral therapy- treatment to fight HIV by taking combinations of ARV drugs (Barrrett-Grant et al, 2001:458).

significant number of individuals. Although not a cure, such treatments are highly effective in rapidly reducing the viral load to undetectable levels, thereby prolonging survival (Whiteside and Sunter, 2000).

It is in this way that anti-retroviral drugs are able to decrease the viral load and prevent the reproduction of the virus in the human body enabling the victims to have prolonged lives. Moreover, research findings show that these drugs are very effective in lowering the risk of transmission of the virus from an HIV positive mother to her infant in pre- and post-natal periods, thus decreasing the risk of MTCT as evidenced in countries like the Brazil, Uganda, North America, etc. (Berger 2001/2:163; www.tac.org.za, 2003:3).

In the absence of treatment and in an attempt to curb the further spread of the epidemic, education, enhancing awareness campaign about the epidemic and its modes of transmission, media campaign, peer education, and the ABCD rules (that is Abstain, Be faithful, Condomise, Do it yourself) are suggested as better options for preventing the spread of the epidemic.

3.3 HIV/AIDS IN SOUTH AFRICA

In South Africa, the first two cases of AIDS were identified in 1982. For the following eight years the epidemic was primarily located among white homosexuals (Whiteside, and Sunter, 2000:47). Nonetheless, with the growing number of infections, the epidemic started to move beyond this circle of the subpopulation of male homosexuals and rapidly infect other population groups such as blacks and heterosexuals. This led to a rapid increase in HIV infection rates especially after 1992. Today, the epidemic has reached extremely high levels among the sexually and economically active population. This makes South Africa a country with one of the highest infection rate in the world killing approximately 600 people every day (www.star.co.za, 2003), thus constituting a major

public health problem that threatens the country's reconstruction and development programmes.

One of the most common means of transmission of the virus in South Africa, next to unsafe sexual practices, has been the mother to child transmission (MTCT) at or around birth and after birth. Every year, tens of thousands of South African children are infected with this deadly virus by their mothers. According to a TAC Fact Sheet published in 2001, during 1999 alone, over 60,000 babies in South Africa contracted HIV through MTCT. Research suggests that a mother to child transmission prevention (MTCTP) program could have prevented between 11,000 and 23,000 of these infections (Treatment Action Campaign, 2001:5).

In South Africa there are certain socio-cultural, economic, and political factors that have contributed to the high prevalence of HIV/AIDS. The migrant labour system is among the widely quoted. Especially during the apartheid era, this means of livelihood has led to the movement of people in search of employment both within South Africa and from neighbouring countries. At a local level, many workers have been moving from impoverished rural areas and former homelands such as Kwazulu and the Transkei in search of employment in the mines. Heinecken (2001) mentions the use of foreign migrants from Lesotho, Botswana, Mozambique, & Malawi (all highly AIDS infected countries) on South African mines. To date, most of these migrants are single men who live separated from their families. Such means of livelihood infers more cases of extramarital relations, promiscuity and an active commercial sex industry, which are likely to have spread the infection to their spouses at home. According to a study conducted in a rural area in KwaZulu Natal, 13% of women whose husbands worked away from home two-thirds of the time or over were infected with HIV. Among women who spent two-thirds of their time or more with their husbands, no HIV infection was recorded (Poku, 2001:196). Thus, "the apartheid migrant labour system that historically tore apart families continues and has been called the 'engine of the epidemic' because it encourages

multiple sex partners" (Workers Vanguard, 2001). Apartheid has further left a legacy of huge disparities between the different racial groups in terms of access to social services, dispossession of resources, forced removals, disruption of family and communal life all of which have created fractured social networks which contribute to today's high incidence of AIDS.

Poverty and economic inequality have also contributed to the high prevalence of the epidemic in their own way. South African society is characterised by extremely high levels of inequality. The distribution of income and wealth in South Africa is among the most unequal in the world (May, 1998). Because many people have poor access to social services such as health care and education, their awareness of HIV/AIDS is low. These high levels of inequality negatively impact on the lives of people, thus in all likelihood contributing much to the high prevalence of HIV infection. And among the victims, there will be those who are doubly victimized by their socio-economic powerlessness. Women and children are those who are most likely to bear/suffer most of the consequences. For instance, of those 4.7 million South Africans who were infected with HIV in 2000, 2.2 million were girls and women aged between 15 and 49 years that is women of childbearing age (Treatment Action Campaign/AIDS Law Project, 2001:5).

Many women's economic security is dependent on their male partners. Due to this unequal power relationship, their ability to have control over their bodies is limited. Their request for safer sex is as a result likely to be ignored by their male partners. This is substantiated by Gilbert and Walker (2002), who have identified the low status of women in society, their subordinate role in the family, their limited resources, and sexual-cultural norms and values (gender inequality), as contributing factors that increase their vulnerability. They further explain that while behaviour patterns cannot be ignored, social inequality may be regarded as the single most important factor contributing to the spread of HIV/AIDS. Thus, for rates of transmission to be reduced, strategies need to address

social inequality generally and the empowerment of women in particular (ibid, 1094).

Last but not least, the lack of consensus within national and provincial government has resulted in tremendous delays in providing free antiretroviral drugs to HIV positive pregnant women, therefore also contributing to the high prevalence of the disease in South Africa. It has lead to the high incidence of death especially among children through MTCT. This delay has been partially due to the denial/dissident position of some key sectors within the national government on the link between HIV and AIDS which has misled many as to whether it was poverty or the HI virus that leads to AIDS (Bond, 2001). South Africa was the only country in the world where government officials have adopted such a dissident stance. Such positions have negatively impacted the national government's ability to effectively combat the epidemic and treat those who live with the virus. For example, until recently and in spite of some evidenced effectiveness of ARVs, in South Africa, key authorities within the government have imposed several restrictions on the availability of these drugs. The government also instigated, as some have argued, unnecessary debates with regard to, for example, the toxicity, cost-effectiveness and side effects of these drugs. Critics indicate that the case has been overemphasised instead of focusing in a policy directed at combating the disease (www.polity.org.za, 2001). The various arguments presented over the past few years by different opinion holders are discussed in detail in Chapter Six.

Generally speaking then, the current scale of the AIDS epidemic in South Africa is a result of multi-faceted socio-economic and historical factors, including a possible lack of political will that has characterized the actions of some government authorities under the pretext of huge cost and ineffectiveness of the drugs in treating the millions of people living with the virus.

A brief on the development of HIV/AIDS	Modes of transmission	Factors that contribute to its high prevalence in South Africa	Treatment and prevention
- early 1980s- an occurrence of unexplained deaths in America, especially among homosexuals and the discovery of HIV- the virus that causes AIDS. - 1982- the first two cases of AIDS were reported in South Africa. - mid-1980s- the first ARVs were discovered. -the current global estimates of people living with HIV/AIDS is about 42 million people (2/3 are in Sub Sahara Africa and about 6-7 million in South Africa)	-unsafe/ unprotected sex, -contact with infected blood, -MTCT (that is during pregnancy, childbirth and breast feeding)	-the migrant labour system, -aprtheid's legacy of huge disparities that led to unequal power relations and subsequent economic inequality and poverty, -unequal gender relations, -the nature of policy responses to provide ARVs that has been characterized by the lack of policy consistency, unreasonable delays, "unnecessary" debates characterized by denial and confusion.	To date no cure exists except ARVs that reduce the viral load and thereby reduce the risk of MTCT both pre- and post-natally. With regard to prevention strategies, education, awareness campaign, media campaign, peer education and the ABCD rules can be employed.

Table 3.1 HIV/AIDS: its historical development, modes of transmission, and factors that contribute to its high prevalence in South Africa

CHAPTER FOUR

HUMAN RIGHTS AND HIV/AIDS: HISTORICAL AND CONTEMPRARY PERSPECTIVES ON CONCEPT, INTERNATIONAL MATERIALS AND INSTITUTIONS

This chapter broadly discusses what human rights are, focusing on their historical developments, their relevance in protecting and promoting the right to health in general and in the context of the HIV/AIDS epidemic in particular. In this discussion, a number of pertinent human rights bodies and documents will be highlighted. It will be found that there is a complex relationship between issues of conceptualisation, formulation and awareness of human rights on the one hand, and the formation and development of human rights bodies on the other. It will be seen that human rights discourses and statutes emerge and evolve in relation to specific challenges under shifting socio-economic conditions. Such processes will be illustrated in relation to the HIV/AIDS pandemic, in the context of the current dominant economic and ideological climate, that is, neoliberalism.

4.1 A CONCEPTUAL HISTORY OF HUMAN RIGHTS

Human rights are “a set of universal elements that individuals enjoy irrespective of their sex, nationality, religion, culture or other status, that are inherent to human beings and that are proclaimed and protected by international law” (London and Patterson, cited in Berger et. al., 2003:51). They allow people to adequately use their qualities as human beings, to realise their talents and satisfy their needs. They are argued to be intrinsic to nature in general and to human nature in particular and to provide the values, principles and standards essential to define and safeguard the most precious of all rights, the right to be human (ibid, 51).

The historical development of current concepts of human rights is often traced back to the 18th Century, culminating in the American Declaration of Independence and the French Declaration of the Rights of Man (sic.). However, it is important to note that many of the core elements of human rights were presented and enforced both in 'Western'[5] and 'non-Western' cultures and societies from ancient times. What the 18th Century brought was a conceptualization of human rights based on the individual rights to life and liberty (UN, 1994:7).

At global level, human rights discourses can be traced back to the adoption of the Universal Declaration of Human Rights (UDHR) in 1948 in the aftermath of the Second World War. Until the tragic event of the War, the pre-war international order had focused solely on relations between states; human rights violations that occurred within a country's borders were considered as internal affairs (Gostin and Lazzarin, 1997:2). The UDHR arose out of international revulsion at the atrocities that were committed during World War II as "the horrors of the War exposed the vulnerability of the individual in an international system that was based on state sovereignty and demonstrated the gross inadequacy of previous attempts to protect the victims of War. The violations were recognized as a grave threat to international peace and security and were linked to the rhetoric of the War and in the plans for peace" (ibid).

As a result, international consensus began to emerge that it was one of the crucial responsibilities of the international community following the Second World War to prevent the recurrence of such horrific threat to peace and human dignity. One of the means to this end was the establishment of human rights laws. Accordingly, "the post-War human rights movement permanently altered the scope of international law" (Cassese, cited in Gostin and Lazzarin, 1997:2). It pierced the veil of national sovereignty and promoted human rights as a matter of international significance, giving recognition to the inherent rights and

[5] Living in or originating from the West, in particular Europe or the US (Oxford English Dictionary, 2003:2001)

freedoms of individuals under international law and holding states accountable for violations (Gostin and Lazzarin, 1997:2). Following the ratification of the UDHR, there has been a widespread adoption of a variety of human rights documents. Since their approval, international human rights have been applied widely, and by the end of the 20th Century become one of the most "globalised political values of our times and their liberal language has moved in to fill the vacuum left by the demise of grand political narratives in the aftermath of the Cold War" (Wilson, 1997:16).

According to the Vienna Declaration and Programme of Action, adopted in 1993 (UN, 1998:40-41), human rights are universal, indivisible, interdependent and interrelated. Irrespective of their various historical, cultural, religious, economic and political backgrounds, signatory states have the duty to promote and protect universal human rights. This concept of state obligation is vital to an effective response in the HIV/AIDS case.

When discussing human rights, the notion of "generations of rights" deserves a special mention. Human rights have been grouped into three different generations of rights. *First generation rights* are those rights that are premised upon the traditional liberal-democratic notion of individual 'freedom from' interference by governments in clearly defined private or personal spheres. Examples are freedom of speech, press, and movement, fair trial and due process of law, the right to privacy and equal protection of the law. In enforcing first generation rights minimal state intervention in the provision of social services (such as education, health care, etc) is required. *Second generation rights* are mainly socio-economic and welfare rights. Examples include the right to basic nutrition and work, basic necessities of life, shelter, the right to education, children's rights, and the right to appropriate health care. *Third generation rights* are mainly 'peoples rights' (or group rights) to, for example, a clean environment, development and self-determination. Unlike first generation rights, second and third generation rights embody

the idea of individual and collective 'freedom towards' promoting and attaining certain social (and global) goals. Moreover, second and third generation rights cannot be positively realised without government intervention (du Plessis and Corder: 1994:24). From the above raised discussion it is clear that the right of HIV infected people to adequate treatment falls within the category of second generation rights.

Public awareness of the different generations of human rights is of major relevance for shaping appropriate responses to the HIV epidemic and other global health challenges, such as developing and offering systems-wide public health responses, and identifying deficiencies in public health research agendas (London and Patterson cited in Berger et. al., 2003:51).

In line with the implicit demands on the role of governments posed by the different generations of rights, it appears that when it comes to making tangible commitments to their realisation, governments tend to be more reluctant in fulfilling second and third generation rights than in the case of first generation rights. This could be explained when considering neo-liberalism, an ideological and economic discourse that characterizes the current global economic climate and has greatly impacted the ability of many 'Third World' countries[6] to fulfill the socio-economic rights of their people. Some of the key policies of neoliberalism are the demand for a *reduction of public spending, privatisation* in which states' intervention in the economy as a producer, owner, deliverer of services is opposed by free market followers. *Deregulation*- that is the demand for the minimal role of the state in economy through the removal of subsidies, price controls, reduction in taxes, and easing/removal of state regulations on business. *Trade and financial liberalization,* which is closely linked with investment agreements and policies to attract foreign investors (Foreign Direct Investment- FDI) by exempting them from certain local laws and taxes,

[6] The developing countries of Asia, Africa and Latin America (Oxford English Dictionary, 2003:1834).

is another key policy of neo-liberalism. As a result of such policies, poor states are dictated to open their domestic markets in a way that encourages mostly international investors at the expense of their local socio-economic priorities. All these policies force poor states to change their economies along the lines of free market.

During the past two decades, one of the main vehicles in forcing 'Third World' countries to abide by this set of neo-liberal policy prescriptions have been the Structural Adjustment Programmes (SAPs), imposed on these counties as part of international loan repayment arrangements. It has become increasingly evident that the universal enjoyment of human rights is jeopardized as a result, in that any significant realisation of the former would require governments to allocate significant amounts from their national budgets towards their fulfillment, which would clash directly with neoliberal policies that force especially poor third world countries to adopt such policies and programmes. For example, from a neoliberal perspective, it would appear that public health budgets are, rather than a productive investment for human development and economic growth, an unnecessary financial burden on governments which should be avoided. The promotion of SAPs in the developing world provides a powerful reminder of this new reality (Poku and Whiteside, 2002:191). Pillay refers to SAPs as a vehicle which was employed "consciously to spread a particular ideology to the developing world - in particular Latin America and Africa by the US-dominated IMF and World Bank, as part of their 'conditionalities' for loans. It was but an extension of neoliberalism to the developing world[7], and included a demand that state expenditure (health, education and whatever meager welfare expenditure existed) needed to be cut drastically" (Pillay, 1999:11-12) (brackets in original).

Within such a context, many socio-economic rights, (for example, the right to basic education, the right to emergency medical treatment, the right of children, etc) which fall under second and third generation rights

[7] In the process of development; (of a country, etc) becoming economically more advanced, becoming industrialized (The New Shorter Oxford Dictionary, 1993:654).

are accorded little weight and are as a result poorly addressed in most of these countries. Such phenomena are manifested in South Africa under the government's GEAR macro-economic strategy which, according to a COSATU policy document brought about deep cuts in government spending. As a result, efforts to improve services to the poor suffered, despite the government's claim of reprioritisation of spending from the rich to the poor. As the taxation of the wealthy has declined, there has been no significant job creation and redistribution, which led to increased poverty and inequality, a phenomenon that is at odds with GEAR's stated objectives such as the creation of employment and the redistribution of income and socio-economic opportunities in favour of the poor. (Knight, 2001). Although not a result of the imposition of SAPs, GEAR resembles the spirit of neo-liberalism and signifies, *inter alia*, an attempt to attract Foreign Direct Investment, an intention which has yielded only questionable outcomes (Sewpaul and Hölscher, 2004).

4.2 GLOBAL RESPONSES TO THE HIV/AIDS PANDEMIC: A DISCUSSION OF INTERNATIONAL HUMAN RIGHTS STATUTES AND BODIES

The growing awareness of the connection between HIV/AIDS and human rights can be traced back to the 1980s when the World Health Organisation's first global response to HIV/AIDS recognized that the protection of human rights was a necessary element of a worldwide public health strategy to confront the then-emerging epidemic (HIV/AIDS and Human Rights, 2002:1). Citing Altman, Berger et al. (2003:59) trace the origin of a human rights-based approach to HIV/AIDS to the US and Europe at a time when most people infected with HIV or at risk of being infected came from groups who were already subjected to discrimination and stigma - such as gay men, sex workers and injecting drug users. It was in the 1990s that human rights approaches came to be seen more and more as a determining factor for people's *vulnerability* to HIV infections, that is "the lack of power of individuals and communities to minimise or modulate their risk of exposure to HIV infection and, once infected, to receive adequate care and support" (www.ippfwhr.org,

2002:1). Hence the degree to which people's human rights were infringed upon determined**,** *inter alia*, their vulnerability to HIV.

The entitlement of human beings to human rights in general and to health rights in particular has been enshrined in various international, regional and national human rights documents which in turn constitute binding obligations to signatory states. Familiarity with the various international human rights declarations, covenants and institutions therefore assists people such as health care professionals, social service workers, NGO-based activists, people living with HIV/AIDS, and government officials in the fight against the AIDS pandemic and related human rights abuses, in developing effective public health policies, and in advocating for a more humane society.

The international body of possibly foremost importance in this regard is the United Nations (UN). Since its foundation in 1945, one of the UN's major concerns has been the promotion and protection of human rights and fundamental freedoms, a commitment which is based on an understanding by the international community that a "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world". Thus, its member states have pledged "to achieve, in cooperation with the UN, the promotion of universal respect for and observance of human rights and fundamental freedoms" (Universal Declaration of Human Rights cited in UN Action in the Field of Human Rights, 1994:1). Accordingly, the UN Charter outlines four purposes of the organization that is, to maintain international peace and security; to develop friendly relations among nations; to cooperate in solving international problems and in promoting respect for human rights; and to be a center for harmonizing the actions of nations (www.un.org, 2003).

There are various UN human rights bodies together with NGOs that are concerned with human rights that have interpreted the HIV/AIDS issue

from a human rights perspective; develop and articulate human rights norms relating to HIV/AIDS; monitor HIV/AIDS-related human rights violations; and advocate for state compliance under the relevant conventions (UNAIDS, 1997:7). For example, the UN General Assembly's Declaration of Commitment on HIV/AIDS notes that "the full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic" (London and Patterson cited in Berger et. al, 2003:53). In an effort to adequately address the HIV/AIDS issue, the Joint UN Programme on HIV/AIDS (UNAIDS) was set up to advocate for global action on the epidemic. This Programme endeavours to lead, strengthen and support an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviating the impact of the epidemic (www.unaids.org.za, 2003).

Another UN body that is concerned with the promotion of human rights is the UN Commission on Human Rights which has recommended for UN bodies dealing with human rights monitoring and enforcement to adopt concrete means to review the protection of HIV - related human rights as part of their specific mandates and procedures (UN, 1996:a). Thus, existing human rights treaties and UNAIDS play a significant role in monitoring compliance with human rights standards in the context of HIV/AIDS. It is in view of this assertion that this section reviews some of the international human rights documents that deal with human rights in relation to health rights.

There is the UN Charter of 1945, a document that articulates in its preamble the international community's determination "to reaffirm faith in fundamental human rights and in the dignity and worth of the human person" (cited in Gostin and Lazzarin, 1997:2). Article 1 of the Charter, as a binding treaty, pledges member states to promote among other things higher standards of living, solutions to international social, economic, health and related problems, universal respect for human

rights and for fundamental freedoms for all without distinction as to race, sex, language or religion (UN, cited in Gostin and Lazzarin, 1997:2). The promulgation of the Charter was followed by the Universal Declaration of Human Rights (UDHR) which represents the organized international community's first attempt to establish "a common standard of achievement for all peoples and all nations" to promote human rights. The document proclaims the equal significance of civil, political, economic, social and cultural rights. The Declaration's 30 articles (see Appendix I) are based upon the principle that "all human beings are born free and equal in dignity and rights" (article 1). The rights are to be respected without discrimination and include, among other things, the right to life. Article 25 of the UDHR explicitly recognizes a claim to health viz:

> Everyone has the right to a standard of living adequate for the health and well being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control (cited in Gostin and Lazzarin, 1997:3).

And the preamble of the WHO's Constitution of 1946 states the fundamental rights of every human being to the enjoyment of the highest attainable standard of health without distinction of race, religion, political belief, economic or social conditions" (cited in Gostin and Lazzarin, 1997:28). The right to an adequate standard of living is an integral component of the right to health. For a person to be healthy, he/she needs adequate food, clothing, housing/shelter, and health care as prerequisites. An inadequate standard of living is most threatening especially to those who live with the virus as they are more easily exposed to opportunistic infections than those who have adequate access to meet these basic needs.

Another international agreement on human rights is the International Covenant for Social, Economic, and Cultural Rights (ICESCR). The Covenant has been adopted by the UN General Assembly in 1996 and signed by 142 countries. It requires signatory states to respect the rights to basic necessities of human life- such as the right to food, clothing, housing, education, and work (Roth, 2000). With regard to health, the Covenant requires states to undertake certain defined steps to meet "the right of everyone to the highest attainable standard of physical and mental health". The steps include:

> a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child; b) The improvement of all aspects of environmental and industrial hygiene; c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness (ICESCR, cited in Gostin and Lazzarin, 1997:5).

It merits noting in this context that although countries like South Africa and the US are signatory to this Covenant, "they have not yet ratified it, evidently for fear of being bound by it" (Roth, 2000:1).

Then, there is the 1998 World Health Assembly's resolution entitled "Avoidance of discrimination in relation to HIV-infected people and people with AIDS", which underlines how vital respect for human rights is for the success of national AIDS prevention and control programmes and urges member states to avoid discriminatory action in the provision of services, employment and travel (UN, 1998:58). According to the UN (1998:39),

> Several years of experience in addressing the epidemic have confirmed that the promotion and protection of human rights constitute an essential component in preventing transmission of HIV and reducing the impact of HIV/AIDS. The protection and

> promotion of human rights are necessary both to the protection of the inherent dignity of persons affected by HIV/AIDS and to the achievement of the public health goals of reducing vulnerability to HIV infection, lessening the adverse impact of HIV/Aids on those affected and empowering individuals and communities to respond to HIV/AIDS.

To the above rights is added the UN General Assembly's request for member states to "promote access of all peoples to appropriate preventive, diagnostic, and therapeutic technologies and pharmaceuticals, and to help make these technologies and pharmaceuticals available at an affordable cost" (UN 1989, in Gostin and Lazzarin, 1997:31). The right for everyone to share/enjoy the benefits of scientific and technological progress is a particularly important health right in the context of HIV/AIDS specifically in view of the rapid advances regarding testing, treatment, therapies, the development of vaccine, and the safety of blood supply, etc. Many technologies have already been developed to prevent, care for, and partially treat HIV/AIDS; many more technologies are needed. Cost-effective innovations such as HIV testing (eg. to screen the blood supply), infection control measures in health care settings (eg. gloves and sterile medical instruments), antiviral medications and treatments for opportunistic infections, strategies to reduce the biological or behavioural risks of transmission, and eventually even vaccinations and cures must be shared globally. As science develops new technologies to combat HIV/AIDS, the need to ensure availability in all countries- poorer as well as richer- becomes more pressing (Parker, cited in Gostin and Lazzarin, 1997:31-32). This right can be related back to the discussion of second and third generation rights, specifically socio-economic rights (see above section 4.1 p.30). It can also be related to one of the ICESR's steps outlined which makes states accountable to undertake measures to meet the right of everyone to enjoy the highest attainable standard of physical and mental health, that is the creation of conditions which would assure to all medical

services and medical attention in the event of sickness (Gostin and Lazzarin, 1997:5)

Finally, there are two documents which speak, *inter alia,* on issues around the promotion of health rights of both women and children, that is, the CEDAW (Convention on the Elimination of All Forms of Discrimination Against Women) and the Convention on the Right of the Child (CRC). The former speaks about women's access to health care services and recognizes "an obligation on state parties to take appropriate legislative, judicial, administrative, budgetary, economic and other measures to the maximum extent of their available resources to ensure that women realize their rights to health care. It further extends to making decisions concerning reproduction" (cited in Berger, 2001/2: 168). The latter speaks, *inter alia*, on issues around the promotion of health rights with specific reference to children, such as taking appropriate measure to diminish infant and child morality, provision of necessary medial assistance to combat disease and malnutrition, and to ensure appropriate pre-natal and post-natal health care for mothers. Both covenants have been ratified by South Africa.

As has been noted, the reviewed documents and international agreements are important tools in the hands of practitioners and activists seeking to advocate human and specifically, health and other socio-economic rights of HIV positive people in general and of HIV positive pregnant women in particular. Yet it remains the responsibility of signatory governments to promote these rights as well as to ensure the conditions that enable people to realize them as fully as possible. Failure to bear such a responsibility would lead to further deterioration of socio-economic rights - rights the realization of which has already been undermined and eroded by the current global market economy.

4.3 THE PROMOTION OF SOCIO-ECONOMIC RIGHTS IN RELATION TO THE PROTECTION OF CIVIL AND POLITICAL RIGHTS

For every human right, governments have responsibilities at three levels: they must respect, protect, and fulfill rights (Gruskin and Tarantola, 2004). This is because only when government responsibilities are met on all three levels, can human rights be realized for all. In addition, "examining the public health through a human rights lens involves looking not only at the technical and operational aspects of public health interventions, but also at the civil, political, economic, social, and cultural factors that surround them" (www.ippfwhr.org, 2002:2) - factors that will be dealt further down in this chapter. In other words, HIV/AIDS policies and programmes can thus be evaluated and improved by systematically reviewing how and to what extent government interventions are respectful of human rights and beneficial to public health (ibid, 2), in relation to their specific context.

Despite the ratification of all the above raised and other relevant international socio-economic human rights documents related to health, the attention given by governments to protecting and meeting them has generally been insufficient. According to the UN (1994:5), it is estimated that in the decade (1980-1989) alone, more people lost their lives as a result of socio-economic deprivation than perished in the Second World War. If all the above raised rights were fully respected, protected and fulfilled, governments would have been in a position of addressing the AIDS crisis far more adequately in that effective preventive strategies would have been widely implemented and access to treatment would have been extended to everyone. Evans (2002:200-201) gives several assumptions upon which the protection of civil and political claims could limit the protection of universal human rights. First, civil and political rights can be guaranteed through the simple expedient of passing national laws that guarantee civil and political freedoms (free of cost). Second, since the extent to which socio-economic rights are realized depends upon the level of economic development a country has

achieved, setting any universal standards for such rights is impossible. Third, socio-economic claims are culturally determined. Fourth, the correlative duty of forbearance clearly rests with all members of society when civil and political rights are claimed but not with socio-economic rights. Last but not least, liberals argue that socio-economic rights cannot be understood as human rights because rights are claimed by the individual, whereas government social policy is concerned with achieving an overall increase in social welfare. Such contestations make finding sufficient national consensus around the allocation of resources so as to address socio-economic rights violations difficult. This, in turn, legitimizes the failures of concerned governments in upholding the rights of their citizens.

It may be for this reasons that in the context of HIV/AIDS, Kenneth Roth (2000), Director of Human Rights Watch, asserts that rights-based arguments in favour of providing the resources needed to fight the AIDS epidemic are ineffective in comparison with arguments related to civil and political rights. In other words, governments tend to give greater priority to responding to appeals concerning civil and political rights violations than they do to problems related to socio-economic rights. Over and above economic considerations, this could be because of the fact that governments are shamed if they fail to address such duties as to stop torture while they are unlikely to be shamed if they fail to provide adequate treatment to AIDS infected people; there is a greater likelihood that such governments are subjected to international and domestic pressure when they do not respect such civil and political rights. Thus, in Roth's (2000:2) explanation,

> the difficulty with invoking socio-economic rights (that is second and third generation rights) is that the duty to respect them is far more qualified than the duty to respect civil and political rights (that is first generation rights), where governments are expected to uphold immediately. Moreover, responsibility for addressing socio-economic rights is assigned almost exclusively to the national government of the country in question;

> there is no opportunity to pass the burden on to others (international bodies). By contrast, the economic and social rights treaty allows its rights to be fulfilled gradually, over time (brackets mine).

As has been emphasized several times already, part of the reason for failing to pass civil and political rights to international bodies lies with the issue of cost. Governments are most often constrained by financial resources and view socio-economic rights as secondary to political and ideological concerns, which relegates rights to instruments of political mobilization rather than regarding them as ends in themselves. The politics of rights therefore contributes to their manipulation rather than to their immediate realization. The result is a fundamental sense of injustice and an abdication of government responsibilities at a global scale. In other words, current calls for the immediate fulfillment of socio-economic rights - or at least their realization within reasonable and foreseeable periods of time - a set in a context of ideological and power relations - that is economic globalisation policies which force governments to liberalise their markets and focus on core activities like creating a proper playing field for investment. As a result, there appears to be a movement away from “social citizenship”, the notion that all members of society have a right to certain social services and programmes, such as health care, education, old age pensions and employment insurance (Teeple, 1995:49-50).

Institution	Human rights covenants and resolutions emanating from this institution
The United Nations General Assembly (UNGA)	- The United Nations Charter, 1945 -The Universal Declaration of Human Rights (UDHR) (1948) -The Vienna Declaration and Programme of Action (adopted by the World Conference on Human Rights, 1993) -International Covenant for Social, Economic, and Cultural Rights (ICESCR) (1996) -The United Nations General Assembly Declaration of Commitment on HIV/AIDS (2001)
World Health Organisation (WHO)	- Constitution of the World Health Organisation -World Heath Assembly's resolution entitled "Avoidance of Discrimination in Relation to HIV-infected People and People with AIDS (Resolution adopted by the World Health Assembly, 1998)
The Joint United Nations Programme on HIV/AIDS (UNAIDS)	
The UN Department of Economic and Social Affairs, Division for the Advancement of Women (DAW)	- Convention on the Elimination of All Forms of Discrimination Against Women (1979)
The UN Children's Fund (UNICEF)	- Convention on the Right of the Child (1989)

Table 4.1 United Nations bodies, declarations and covenants related to HIV/AIDS

CHAPTER FIVE

HUMAN RIGHTS, PUBLIC HEALTH AND SOCIAL WORK: CHALLENGES TO SOCIETAL POWER RELATIONS

This chapter broadly discusses the concept of public health in relation to human rights and the Social Work profession. It further seeks to illuminate the complementarity and mutual reinforcement between the former two concepts and the role of the Social Work profession in realizing people's access to health care services. It will be found that the three concepts played a significant role in transforming existing power relations and redressing power imbalances and thereby fulfilling human rights in general and ARV rollout to HIV positive pregnant women in particular. In so doing, advocacy, empowerment, and the social action approach are employed as mechanisms.

5.1 THE COMPLEMENTARY RELATIONSHIP BETWEEN HUMAN RIGHTS AND PUBLIC HEALTH

The Institute of Medicine, which is based in Washington, defines public health as:

> What we, as a society, do collectively to assure the conditions of people to be healthy. This requires that continuing and emerging threats to the health of the public be successfully countered. These threats include immediate crises, such as the AIDS epidemic; enduring problems, such as injuries and chronic illness; and growing challenges, such as the ageing of our population and the toxic by-products of a modern economy, transmitted through air, water, soil, or food. These and many other problems raise in common the need to protect the nation's health through effective, organized and sustained efforts led by the public sector (cited in Gostin and Lazzarin, 1997:29).

Building on this definition, the right to health translates into "the duty of the state within the limits of its available resources, to ensure the

conditions necessary for the health of individuals and populations" (ibid). This requires governments and public health authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time. To ensure that this happens is the challenge facing both the human rights community and public health professionals.

The concepts of human rights and public health have been said to be both of a competing and a complementary nature. According to Mary Robinson, the UN Higher Commissioner for Human Rights, quoted in WIN News (2003:2), public health encompasses efforts by the state to ensure the conditions under which people can be healthy, which may include government interventions in the lives of individuals to protect the community's health. In this regard, human rights are employed to promote and protect individual's rights against the state's interference or abuse. Thus, the two concepts may compete: human rights protect the rights of individuals, and public health protects the collective good. The complementary nature of the two concepts is a recent phenomenon. This is partially due to the evolution of state responsibility for promoting and protecting human rights in the recent past (Gostin and Lazzarin, 1997:1). This complementarity can be seen in the similarities of objectives both human rights and public health share, that is the promotion and protection of the wellbeing and health-related entitlements of all individuals. From a human rights perspective, public health objectives can best be attained by promoting and protecting the rights and dignity of everyone, with special emphasis on those who are discriminated against or whose rights are otherwise interfered with. Likewise, human rights objectives can best be accomplished by promoting health for all, with special emphasis on those who are vulnerable to threats to their physical, mental or social wellbeing (UN, 1998:39).

Evolving approaches to public health emphasize, among other issues, "respect for individual rights, trust between public health personnel and

the community, access to adequate health care and education, as well as conditions of non-discrimination" (Gostin and Lazzarin, 1997:43). Human rights, as has been discussed in section 4.1, constitute a set of rights which people hold throughout their lives, and which "embody fundamental claims to life, liberty and equality of opportunity that cannot be taken away by the government, persons, or institutions" (ibid: xiv). The protection of these rights is indispensable for the protection and promotion of public health in general and in the fight against the AIDS pandemic in particular because all people share an inherent worth and dignity which sometimes transcends even their own desire to be healthy (ibid). Thus, a human rights approach is important not only because it promotes respect for individuals but also because such respect is crucial to improve public health and wellbeing. This view is supported by Mann et al (cited in London, 2002:2), who outline a triangular relationship between human rights and public health in that:

> -Health programmes and policies are recognized as having a major potential impact on human rights, both beneficial and adverse;
> -Human rights violations lead directly and indirectly to adverse health impacts;
> -The promotion of human rights and the practice of public health are complementary and indivisible approaches to protecting and advancing the wellbeing of people.

In other words, respect for human rights and advancement of public health go hand in hand and mutually reinforce each other as people cannot fully enjoy their human rights if they are not healthy, and they cannot remain healthy if they are deprived of their rights (Gostin and Lazzarin, 1997:iii).

In the context of HIV/AIDS, 'human rights-based approaches to health' are closely related to attempts to combat the spread and impact of the epidemic around the world. A 'human rights-based approach to health',

thus refers to the process of "using human rights as a framework for health development; assessing/addressing the human rights implications of health policy, programme or legislation; making human rights an integral dimension of the design, implementation, monitoring and evaluation of health-related policies and programmes in all shapes, including political, economic and social….." (WIN News, 2003:2). Recognizing the connection between HIV/AIDS and human rights is crucial for the development of rights-based approaches to intervention and prevention strategies, for example, when dealing with issues like stigma and discrimination which could limit the access to services of those infected with the virus. A failure to protect people living with HIV against stigma and discrimination may lead to subsequent difficulties when trying to reduce the risk of transmission as this firstly limits openness among those infected, and secondly serves as a disincentive to HIV testing amongst people whose behaviours may place them at risk. As a result, a lack of protection and respect for human rights can fuel and exacerbate the spread of the epidemic. In other words, in a world of AIDS, "the lack of human rights protection can become a matter of life and death. Conversely, safeguarding those rights can enable people to avoid infection or, if already infected, to cope more successfully with the effects of the epidemic" (UNAIDS, 2002:62). Thus, there are three reasons why the protection and promotion of human rights are essential to preventing the spread of HIV/AIDS and to mitigating its socio-economic impact: firstly, it contributes to the reduction of vulnerability to HIV infection by addressing some of its root causes; secondly, it lessens the adverse impact on those infected and affected by HIV; and thirdly, it contributes to the empowerment of individuals and communities to respond to the pandemic (HIV/AIDS and Human Rights, 2003:1). Supporting a similar argument, Mann (1999:224), explains the major advantages of adding a human rights dimension to HIV prevention work to include that of acting at the deeper level of societal causes to help uproot the pandemic; linking health issues with the mobilizing power of human rights and expanding the ability of people to see the connection between rights issue and their

health; enhancing the capacity for cross-disciplinary work; and revitalizing global thinking within the collective response to HIV/AIDS.

5.2 CONTESTING SOCIETAL POWER RELATIONS: THE ROLE OF HUMAN RIGHTS DISCOURSES

Above, it has been noted that respect for the general principle of human, including socio-economic, rights is a widely accepted norm, the situation differs when it comes to policy implementation. The explanation given so far has been that the current global economic and ideological context has made the translation of human rights into appropriate policy choices extremely difficult, especially in 'Third World' countries (see above p.32). However, as the term '*policy choices'* implies, there may indeed be alternatives available to governments, even in the 'Third World' that are often not acknowledged. In order to explore this complex further, it is important to consider that human rights cannot be seen separately from power relations, and realizing, for example, health rights, beyond making general commitments may imply the need to alter existing forms of governance and the exercise of power. Thus, "although rights may constrain the exercise of power, power sometimes leaks out and flows around rights" (Wilson cited in Graham, 2000:1). It therefore becomes difficult at the same time as it becomes a necessity, for social activists to attempt to exert political influence on relevant government authorities precisely to propel forward the progressive realization of socio-economic rights such as health rights. With regard to the issue of HIV/AIDS, it has been suggested that the power of political leaders lies in three areas: in exerting influence through formal state/government systems, in shaping discourse, and in providing moral authority (African Development Forum, cited in Schneider, 2002:161). In addition, the power to allocate public resources is of particular relevance.

When seeking to influence national governments around issues of public health in relation to HIV/AIDS, it is important for social activists to give consideration to the relationship between human rights and power. Hunt

(cited in Graham 2000:1) sees rights as a type of law, which represent an important vehicle for challenging existing power relations. Legislation can be used both to sustain and challenge power relations, and one of the most important vehicles in this regard would be human rights. This is because, once awareness has been raised that people have rights, human rights discourses can be employed with the intention of influencing people so as to develop and strengthen their belief that they need these rights to be realized and protected, hence motivating people to engage in social action[8] around such causes- Hunt cited in Graham (2000). Thus, the language of rights provides a framework for which and in which political struggles are fought. By their very nature, human rights could therefore act as a means to either reinforce or transform existing power relations in favour of those who are powerless.

There are a variety of cases that demonstrate how disadvantaged groups and civil society organizations have mobilized around social reform issues and had victories by, *inter alia*, referring to human rights. Examples are the land restitution of dispossessed local communities like the Makulele of South Africa who regained their land (www.fordfound.org, 2004); and the success of the TAC against the Minister of Health where the Constitutional Court ruled in favour of the provision of ARVs (refer to Chapter Six p.68-69) even though the government 'dragged its feet' in providing these drugs.

Examples such as these signify a number of important aspects which need to be considered if such actions are to be successful. Hunt (cited in Graham, 2000) points out the role of civil society in developing and strengthening collective identities on the basis of which people can be mobilized with a view to enforcing their collective entitlements. In other words, the degree of success of legal mobilization is largely determined by the development of influential organizations in civil society that are

[8] a process directed at the less privileged segment of the community which has to organize to make greater demands in society at large for more resources and also to demand treatment which is in agreement with justice or democracy (Perlman and Gurin, cited in Lombard, 1999:91).

capable of taking up social reform issues and pushing for their realization (Graham, 2000:8).

In this regard, the experience of post-apartheid South Africa has been that the existence of constitutional mechanisms to promote civil, political, and socio-economic rights is tremendously important for the poor and otherwise marginalized people in society and can serve as a critical tool for such organizations to redress power imbalances and inequities. Another author, Trend (1996), stipulates that the civil society organizations can use the idea of liberal democracy, which the South African Constitutional Court emphasizes in claiming peoples' rights.

Schreingold (1974) emphasizes the need for members of civil society to depend on their own when working towards the realization, protection and promotion of their human rights to ensure that they achieve their goals of claiming the rights people are entitled to. The politics of rights involves a language of entitlement so as to effect political mobilization which is expected to lead to social change. In order to claim their entitlements, people need to be activated, organized and realigned around specific issues (ibid). Activation means that civil society has to become aware of disadvantaged group's problems and to realize that its members are entitled to human rights. This involves firstly, developing awareness of the political problems people are facing, while receiving education about their rights and entitlements towards the government. Once people realize that they have certain rights and entitlements and that they need to claim and protect them, they can organize into groups (such as NGOs, CBOs, grassroots organizations etc) as well as align with other forces (be it political organization or social forces - eg. lobby groups) to reach their goals. One such alliance partner would be the profession of Social Work.

5.3 SOCIAL WORK AS A CIVIL SOCIETY ORGAN: ITS ROLE IN PROMOTING HUMAN RIGHTS

In view of the assertion that social workers could serve as potential alliance partners for broader civil society organizations when challenging the abuse of power and trying to ensure that people's unmet needs are met, questions arise as to the nature of Social Work viz-à-viz concerns around human rights, public health and strategies such as the ones discussed above. Broadly speaking, the role of Social Work, a profession that promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance wellbeing, (IFSW - International Federation of social workers cited in Hölscher, 2001:39) in regard to the progressive attainment of human rights by disadvantaged and marginalized persons and groups is indeed crucial. Principles of human rights and social justice are fundamental to Social Work's mission, which is to enable all people to develop their full potential, enrich their values, and prevent dysfunction. Professional Social Work is focused on problem solving and change. As such, social workers are change agents in society and in the lives of individuals, families and communities they serve.

Social Work may be conceptualized as an interrelated system of values, theory, and practice (International Federation of Social Workers, 2003:1). As far as its values are concerned, according to the International Federation of Social Workers (2004:1),

> Social Work grew out of humanitarian and democratic ideals, and its values are based on respect for the equality, worth, and dignity of all people. Since its beginning, the profession has focused on meeting human needs and developing human potential. Human rights and social justice serve as the motivation and justification for Social Work action. In solidarity with those disadvantaged, the profession strives to alleviate poverty and to liberate vulnerable and oppressed people in order to promote social

> inclusion. Its values are embodied in its national and international codes of ethics.

In other words, Social Work's theory, practice, values and ethics are inseparable from human rights. Rights corresponding to human beings have to be upheld and fostered, and provide a central moral and ethical justification of and motivation for Social Work action. Advocacy of such rights must therefore be an integral part of Social Work when mediating between the people and the state and other authorities and when providing protection in cases where state action threatens the rights and freedoms of people (UN, 1994:5). In this regard the need for Social Work to move to a consideration of human rights as an organizing principle becomes crucial. It is for this reason that human rights and social justice[9] discourses have served to influence and change Social Work so as to create a profession that works towards transforming society in favour of the marginalized and poor.

Social Work "bases its methodology on a systematic body of evidence-based knowledge derived from research and practice evaluation." It draws on theories of human development and behaviour and social systems to analyse complex situations and to facilitate individual, organizational, social and cultural changes (ibid). Social Work practice comprises a variety of skills and techniques, and activities consistent with its holistic focus on persons and their environments. The scope of Social Work intervention, according to the Federation, ranges from crises and emergencies over everyday personal to general social problems, from concern with psychological processes to involvement in social policy, planning and development as well as agency administration, community organization and engagement in social and political action (ibid, cited in Hölscher, 2001:39). Social workers have historically practiced in a broad range of fields of service, one of which has been health care. Citing Carlton, Dubois and Miley (1999:330),

[9] The embodiment of fairness, equity and equality (Encyclopedia of Social work, 1995:2176).

describe the profession's contribution to health care as one which enables people who are ill/disadvantaged to maintain/regain an improved standard of living that helps them make a positive contribution to the communities of which they are a part.

In other words, the Social Work profession has over the past century developed a scientific stock of knowledge in a range of fields, and based on this, continuously tried to refine its practice methods. Its goals, that is, the ends towards which its methods are applied in these different fields of practice, provide the profession with its legitimization and are in turn informed by the profession's value base, and thus, centrally, notions of human rights and social justice. Cutting across Social Work's different fields of service and practice methods, are several approaches which - though they may have in the course of the profession's history remained marginal strands - speak particularly well to the concepts of human rights and social justice (Sewpaul and Hölscher, 2004).

Similar to Schreingold's (1974) argument discussed in previous section, a rights-based approach in Social Work seeks to improve the effective rights of disadvantaged groups in society by employing a threefold approach (Ife, 1995). Firstly, people must be helped to know their rights because many directly concerned people do not know exactly what human rights are guaranteed by national legislation and international agreements. Secondly, people must be helped to define and assert their rights. Often, rights can only be realised if they are effectively claimed, and many people lack the knowledge, resources, and skills to do so. Thirdly, people must be helped to realise and exercise their rights, which requires skills of activism and the capacity to use one's existing rights to maximum effect (Ife, 1999:71-72).

This rights-based approach in Social Work can be achieved mainly through the *empowerment* approach which is a complex means to help clients develop increasing degrees of personal, interpersonal and collective forms of power which in turn allows individuals, families,

groups and communities to maximize their quality of life (Potgieter, 1998:216). The term 'empowerment' used in the above context is central and requires further elaboration. According to Mancoske and Hunzeken (cited in Lee, 1994:13), empowerment refers to "using interventions which enable those with whom we interact to be more in control of the interactions in exchanges…. and the capacity to influence the forces which affect one's life space for one's own benefit". Since long empowerment has been a central part of the Social Work profession and social care in serving its clients. To this effect, citing Simon, Dhopper (1995:228) identifies some components of the empowerment approach such as the recognition of clients' rights, responsibilities and needs and the direction of professional energies toward helping those who are historically disempowered individuals and groups.

Linked with this is the notion of *conscientisation* (Freire, cited in Lee, 1994). This is a complex intervention form which was originally developed for social activists and adult educators and has since been assimilated into the methodology stock of Social Work. *Conscientisation* seeks to provide the conceptual and methodological tools for moving with a given community through a process from a state of unawareness of structural forms of oppression to a state in which clients are able to take action towards their liberation.

Social action is a community work method, which seeks to provide the necessary tools for collective action towards the attainment of, for example, human rights, - social justice - or development related goals (Lombard, 1999). This method lends itself particularly well to situations of structural disadvantage and systematic oppression.

Lastly, there is *advocacy,* an approach which is used by Philip (cited in Payne, 1997:270), to imply the aspect of Social Work that 'represents' in the sense of interpreting or displaying the value of clients to powerful groups in society. So it can mean a service arguing clients' views and

needs, a set of skills or techniques for doing so and the interpretation of powerless people to powerful groups.

With regard to structural disadvantage, Ife (1995:62) refers to "the importance of the three principal forms of structural disadvantage in Western societies, namely class, gender and race/ethnicity. Each can be seen to be fundamental, in that they are all-pervasive and identifiable in most if not all social issues social problems and inequities". He further asserts that there are other forms of disadvantage, like disability, poor health and old age: "These forms of disadvantage are not the result of … structural oppression,…. and people in these groups will almost inevitably be further disadvantaged if they also happen to be poor … or women" (ibid, 63).

In terms of this conceptualisation of social justice, HIV positive pregnant women may be considered structurally disadvantaged, with the extent of their disadvantage increasing along the lines of their economic status, along the urban-rural and race divide as well as the progressive worsening of their overall health as a result of HIV. In other words, social justice has yet to be realised for this group, in light of the apparent refusal, until recently, of key position holders in government to make ARVs available to this group, thereby giving effect to their constitutional right to access to health care services. This may be interpreted as one indication of their structurally disadvantaged status. Therefore, the roles of vibrant civil society organisations and other relevant groups that are concerned with the human rights of HIV/AIDS infected persons are crucial in determining the success of attempts to use rights-based arguments in the context of a legal mobilisation to ensure that government adopts a coherent stand to make an irreversible commitment to a public sector antiretroviral rollout program.

In this regard, the role of the Social Work profession is of paramount importance. The profession can intervene by employing some of the practice methods and approaches reviewed in this section so as to

enhance peoples' competence and functioning, to deliver support and the desired social services and resources, and last but not least, help marginalized members of society overcome structural forms of oppression with the purpose of promoting social justice through the development of social policy.

In the South African context, where the realization of human rights cannot be separately seen from power relations and ideological contestations, Social Work can indeed join other organs of civil society in their endeavor to apply human rights discourses, with a view to addressing the as yet unfulfilled health rights of people living with HIV/AIDS. In so doing, the discipline can employ its code of ethics, which states, *inter alia,* the obligation to render service professionally and enhance and promote service-rendering to the community under all circumstances by utilizing and developing resources in the community (Potgieter, 1998:45,47). Besides, in transforming existing power relations and realizing such an end, the profession can use its role and methodology to enhance peoples' wellbeing and improve the attainment of their rights and prevent dysfunction in society partly through legal mobilization, social action approaches, using skills and revitalizing local and global thinking.

From engaging with the whole discussion in the chapter, it is generated that there exists a complementary relationship between human rights, public health and the Social Work profession. This complementarity and mutual reinforcement can be drawn from, for example, in the Social Work case, the discipline's values, knowledge and skills base. In this regard, the values base is informed by a human rights discourse which overlaps with other discourses such as social justice and empowerment approaches which in turn inform the direction towards which skills are used, for example, conscientisation and social action towards the better attainment of human rights (in this regard, the provision of ARVs to HIV positive pregnant women). This links the general human rights discourse

with the provision of ARVs. Human rights are therefore employed to promote and protect people's right against the state's abuse.

The resultant conclusion, however, is that through the use of Social Work strategies, human rights discourses can be employed so as to challenge and shift existing power relations which will ultimately lead to certain changes in the arena of public health. While Social Work strategies have been referred in some detail, the following chapter will investigate the position of different stakeholders (both from within and outside government) with regard to ARV provision to HIV positive pregnant women. This will be seen in light of local and international human rights instruments, the law and various other mechanisms that were employed by activist groups, and the subsequent processes that have led to the provision of the drugs.

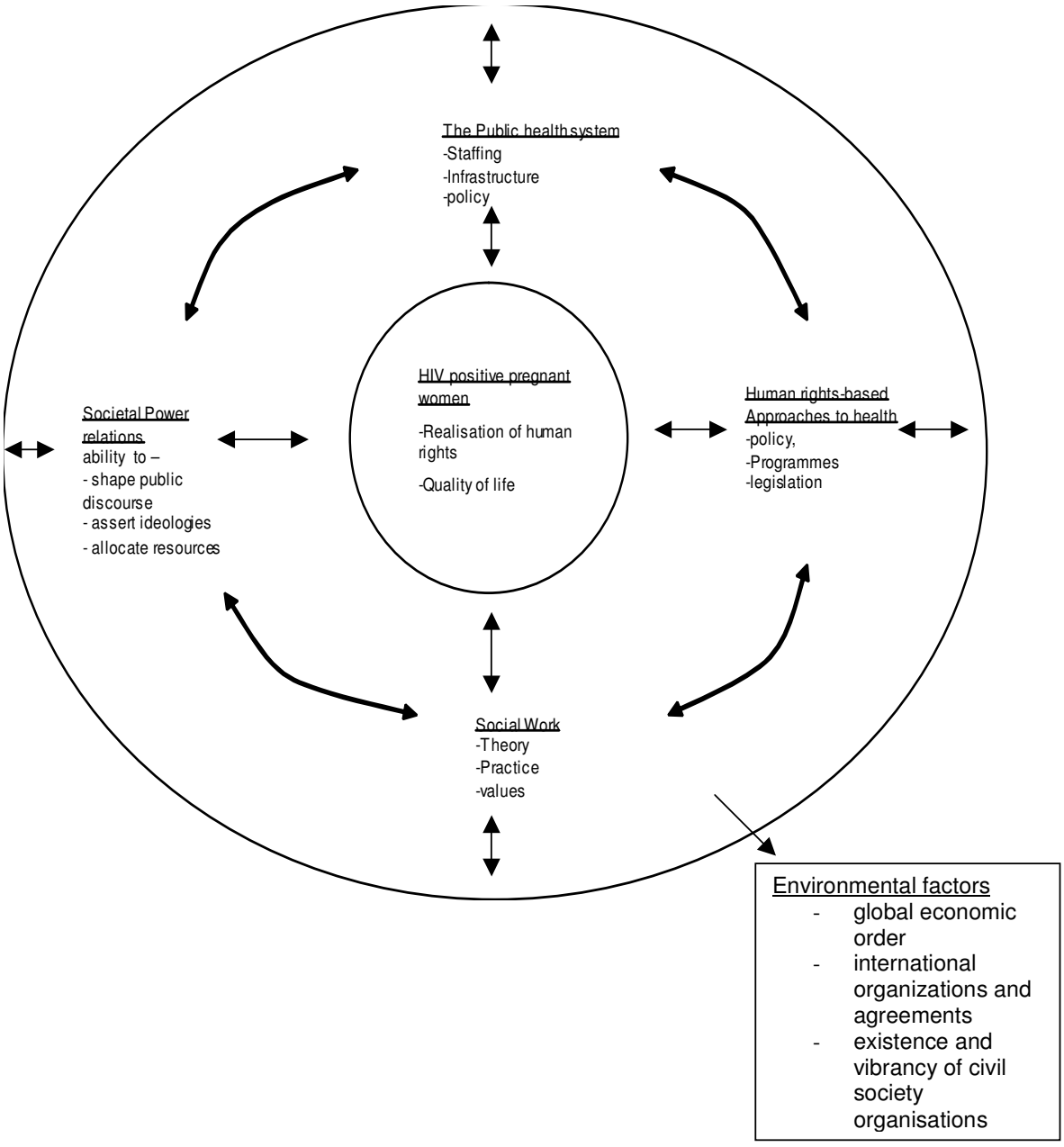


Diagram 5.1 The complementary relationship between public health, human rights, Social Work and societal power relations

CHAPTER SIX

THE DEBATE SURROUNDING A COMPREHENSIVE PROVISION OF ANTIRETROVIRAL DRUGS TO HIV POSITIVE PREGNANT WOMEN IN SOUTH AFRICA (1999 - 2004)

In this chapter the heatly debated issue around the provision of ARVs that has run for the last five years between some key authorities within the South African government (for example, the national Minister of Health and the different provinces such as Eastern Cape, Western Cape, Gauteng, Kwazulu Natal) and the different bodies outside of government (for example, local and international civil society organizations, AIDS activists, and trade union representatives) will be closely examined. Their positions will be outlined in relation to human rights discourses and legislations. Moreover, the different factors and processes that have led to the adoption of a homogonous position within the national government will be highlighted. It will be found that in challenging government's position with regard to the provision of ARVs, civil society organizations employed strategies of social action and advocacy that ultimately led government to start rolling out the drugs.

South Africa has evolved from a country that protected the rights of few to a country that endeavours to protect the rights of all its citizens equally. At an international level, it is among those countries that are signatory to many of the international human rights documents discussed in Chapter Four. Its Constitution enshrines civil, political, and socio-economic rights. However, as has been argued in the previous chapters, a principle commitment to these rights does not automatically translate into adherence in practice. It requires a particular interplay of discursive and legal action, as well as a combination of public debate, consciousness raising and social action to successfully claim the realization of human rights for marginalized members of society. The debates and processes reviewed below will demonstrate the relevance of this claim in practice.

It has been noted earlier on that South Africa today has one of the highest number of people living with the HI virus in the world, the biggest health threat it has ever met in its history. When analysing the multifaceted factors that contribute to it has been found that there might be certain ideological contentions and power constellations unfolding in the legal and political landscape of South Africa that contradict the government's claim to exercise full commitment to democracy, work towards the fulfillment of social justice as well as to oblige to all of its constitutional duties.

It is in the context of the epidemic's threatening size that one of the major policy debates in health care has focused on the provision of antiretroviral drugs, mainly Nevirapine, an ARV, which is believed to significantly reduce the chance of a newborn baby contracting HIV from his/her HIV positive mother. Since the discovery of these drugs many countries have made them available in their health centres and have shown a significant reduction in the number of their AIDS cases and reduction in the stigma associated with the disease, with the number of people undergoing HIV test increasing as a result (refer to Chapter Three section 3.2). However, this is not the case in South Africa, where key position holders within the national government have until recently imposed several restrictions on the wider availability of these drugs in public health sectors for reasons that are discussed further below in this chapter. Such positions were based on complex arguments and have been contested both within and outside government. Outside government, dissent stance has been opposed by NGOs/pressure groups such as the Treatment Action Campaign (TAC) and the Health Systems Trust, trade unions such as the Confederation of South African Trade Unions (COSATU) but also found expression in several public demonstrations and marches. Within government, the different stances taken at different points in time by different authorities seem to suggest at least an absence of consensus on the issue. The differing positions of the Minister of Health and some key personalities in different provinces (such as the Eastern Cape, Western Cape, KwaZulu Natal and Gauteng) are mentioned as cases in point in this regard (refer below p.72). The insight we can draw from this is that until recently, there seems to have

been a lack of coherence between national and provincial policy, as to whether antiretrovirals in general, and Nevirapine in particular, should be given to HIV positive pregnant mothers.

In order to develop a thorough understanding of the debate around the provision of ARVs for HIV positive pregnant mothers that has been ongoing throughout the last five years it is crucial to develop a thorough understanding of the different views and perspectives involved as well as those factors which eventually led to the resolution by government in November 2003 and April 2004 that ARVs should be made universally available to HIV positive pregnant mothers.

6.1 CONTESTING POSITIONS IN THE DEBATE

There are firstly those who have held the position that the South African government should not rollout these drugs due to:

-The side effects of the drugs since they were said to be toxic,
-The lack of adequate scientific evidence showing their effectiveness in reducing the rate of HIV infection,
-The relationship between poverty and AIDS,
-The expense that would follow once they were approved to be delivered in state hospitals, and
-The operational challenges in terms of testing, counseling, disposing of the drug, follow up services, etc (www.polity.org.za, 2001).

With regard to the drugs' *side effects,* the opinion has been presented that these drugs can be toxic and directly detrimental to a natural immune response to HIV. This immune response, observed in long-term survivors, maintains control of HIV replication without the need for antiretroviral therapy (ibid, 2001). Some "dissident" AIDS scientists have also suggested

that the toxicity of AZT, an ARV, might be the cause of AIDS (Schneider, 2002:148).

As far as their *effectiveness* is concerned, it has been claimed that it is yet to be proven that these drugs do really fight the virus. The Director of the National Institute of Allergy and Infectious Diseases (NIAID) Dr. Anthony Fauci was once quoted as saying "there is an increasing percentage of people in whom after a period of time, the virus breaks through, people do quite well for six months, eight months or a year, and after a while, in a significant proportion, the virus starts to come back" (www.polity.org.za, 2001). Therefore, due to the alleged side effect and non-effectiveness of these drugs, it has been claimed that in spite of withholding access to ARVs, government is not depriving the right to treatment of those living with the virus. Instead, reference has been made to the government's commitment to improving the range of health care services and treatments available to those living with the disease. There has been specific reference to government's commitment to the Health Act, which aims to "promote the health of the inhabitants of the Republic so that every person shall be enabled to attain and maintain a state of complete physical, mental, and social well-being" (Barrett-Grant, et al, 2001:146 -147).

By and large, the National Department of Health has stated that it recognizes the rights of each individual as enshrined in the Constitution. With regard to ARVs, it has made reference to human rights and ethics in administering such drugs. It has further claimed that a published body of research existed which implied the harm of these drugs. In other words, because it would be unethical to administer them and because they had not been properly tested through a controlled study thus, by implication, not administering them would be tantamount to recognizing the constitutional rights of people (www.polity.org.za, 2001).

We have to consider another perspective in this argument- *the relationship between poverty and AIDS.* It has been claimed that AIDS is an issue of poverty rather than the result of HIV infections, as popular scientific

orthodoxy would have it. President Mbeki has reportedly referred poverty as the main cause of the many premature deaths among black South Africans: “we cannot blame everything on a single virus. Poverty is the underlying cause of reduced life expectancy, handicap, disability, starvation, mental illness, suicide, family disintegration and substance abuse” (cited in Schechter, 2004). This has been seen as a policy conclusion by some conservative AIDS dissidents / denialists who deny the causal link between HIV and AIDS. Such a position have aroused national and international outcry as it countered the generally uncontested view that HIV causes AIDS.

With regards to the *costs*, there were until recently doubts as to whether the state could afford to carry on implementing the proposed programs on the basis that it would be expensive. In one instance, the Minister of Health Dr. Manto Tshabalala Msimang said that if the public sector doctors would prescribe Nevirapine, the health system would be thrown into chaos and that “budgeting distortions” would result (Anstey, 2001). When addressing a conference in March 2001, the Minister said, “there is, needless to say, growing pressure for the use of antiretrovirals on a much wider scale in South Africa. Our position on this matter is clear: at current prices we simply cannot afford to give antiretroviral therapy in the public sector” (Alfreds and Jacobson, 2003). Citing Nyazema, London, (2002:4) links this argument of affordability with the concept of social justice by arguing that in providing the drugs government would effectively “meet the needs of a highly vocal, well organized lobby groups and, by so doing, neglect the needs of less vocal, poorly organized, and more marginal groups, thereby increasing inequality”. Similarly, the Kwazulu Natal Minister of Health on occasion at the 2000 International AIDS Conference challenged his audience by asking, “…what if we have money for antiretrovirals but no money for clean water? How do we then treat diarrhea?” (Mkhize, cited in London, 2002:4). This clearly frames the provision of antiretrovirals as unaffordable and not a priority health programme because it would exclude the possibility of more basic health care resources. The issue at stake here is that two socio-economic rights are ‘played out against one another’, that

is to suggest that government can only either afford clean water or life-saving drugs. Yet it has been argued above that different human rights by their very nature are mutually reinforcing (refer to Chapter Five p. 46). This suggests that Mkhize's argument may be considered essentially manipulative. Thus, apart from the real cost of the drugs, cost of the infrastructure of care such as HIV testing, counseling, follow up, etc, has been argued to be a hindering factor to provide ARVs. It may therefore be argued that the government's emphasis on cost has effectively led to the double victimization of the poor who as a result of this logic have been alluded neither access to basic health care services (such as those which depend on the availability of clean water) nor to ARVs.

Government has frequently pointed out that there are already 18 research and training sites servicing and providing more than 200 contact points for pregnant women. For example, for the year 2000, R25 million had been set aside nationally for the prevention of MTCT programme and augmented by the provinces. The Minister of Health on its part it has implemented health promotion strategies such as the R90 million communication campaigns to build public awareness and to prevent the spread of the disease, as well as to mobilise involvement in caring for and protecting the rights of those affected. The Minister of Finance also argued that his office had increased HIV and AIDS spending through the funding of dedicated national AIDS programmes. Furthermore, the health allocation to provinces had increased to strengthen the capacity of hospitals and clinics to cope more effectively with increased demands for services. Allocation for infectious diseases would be increased substantially as well (Treatment Action Campaign, 2001). These efforts may, however, be considered minor when seen in light of the looming threat of the epidemic and when compared against government expenditure on other sectors for example military rearmament (refer to Chapter Seven, section 7.1 p. 83).

According to a government document, The Operational Plan for Comprehensive HIV and AIDS Care, Management, and Treatment for South Africa (2003:18,21,24), that aims to "accomplish comprehensive care

and treatment for people with HIV and AIDS and to strengthen the national health", the South African Constitution requires that government implement ARV rollout programme be carried out in a universal and equitable manner. Moreover, to make this programme sustainable, the Plan emphasizes on cost effectiveness and efficiency, *without compromising quality* (emphasis mine). Yet, government's emphasis on 'cost' may be regarded as unreasonable and unjustifiable when seen in the light of the following explanation:

> If 1.4% of GDP over a period of one year will extend the lives of 30% of the South African HIV positive population (3% of the total population) over one year, it seems reasonable to ask why aiming for 100% coverage of the HIV positive population (or over 10% of the total population) at less than 5% of GDP should be fiscally unsound (Geffen, cited in Kelly et al, 2002:143).

Many groups involved in the debate such as the TAC and others have strongly criticised government reluctance as effectively denying people's right to treatment. COSATU has claimed that concerns around cost are understandable but often exaggerated. In any case, they cannot be used to deny treatment for the millions of poor victims who could not afford to buy the drugs. Others like Professor Nicoli Natrass, a health economist, have explained that the provision of the drug would indeed save government money (Blaine, 2002). But the state has repeatedly reiterated its position that the demand for such drugs on a national scale would put major pressure on its resources.

It is important to point out that HIV positive pregnant women have access to ARV treatment even in lower/middle income Third World Countries like Uganda, Botswana and Brazil (refer to Chapter Three section 3.2). In addition, it merits noting that in 2000, when the manufacturers of Nevirapine made the drug available free of charge for a period of five years, the South African government failed to take advantage of this space (Bond, 2001:179). The logic behind this stance, in Bond's explanation,

transcends the cost of antiretroviral drugs to include the class/race/gender-biased character of South African health and social policy under conditions of a failing neoliberal economic strategy that is inhibiting prevention (ibid; also refer to Chapter Four section 4.1). This suggests that the delay in the provision of ARVs has not only been caused by the different pharmaceutical corporations in their provision of the drugs at high price but also by the government's overall socio-economic policy. It appears, that government's argument that the money spent on these drugs could obstruct its coffers and undermine its economic development programs. However, it has already been found that these have been formulated under conditions of globalization and neoliberalism, which include among the latter's components minimal state intervention in the provision of social services, such as basic healthcare. In other words, while many of the overt arguments justifying government delays in rolling out a wider ARV programmes pertain to the various cost factors involved - when seen in context, clearly, such arguments appear to be unsustainable. Thus, it may be concluded that underlying the cost argument is an absence of political will.

Finally, it is important to note on government policy responses to the epidemic which have been characterized by a lack of political leaders' decisive leadership and unproductive conflict between state and civil society, reluctance to prioritise AIDS treatment and prevention, and highly uneven programme implementation through a quasi-federal political system. Schneider and Stein (cited in London, 2002:2) refer to the complexity of the situation in South Africa when claiming that such impediments result from firstly, the structural weaknesses of the state bureaucracy inherited from apartheid, and secondly, the independence of provincial spheres of governance in a quasi-federal political system. This political system coupled with - until recently - the absence of coherence within the national government as far as the provision of ARVs is concerned, has led several provinces to rolling out the drugs on their own despite the Ministry of Health's reservations regarding their side effects, huge cost, and operational challenges in distributing them effectively**.** This

has caused significant regional inequities. In addition, the absence of a coherent approach to the issue has effectively promoted inequity in that richer groups have been able to buy adequate health care while persons relying on public health provision have been denied similar levels of provision. As a result, state legitimacy has been questioned by NGOs, civil society organizations and some organs within the national government itself.

6.2 ARGUMENTS AND PROCESSES LEADING TO THE PROVISION OF ARVs

In refusing the universal rollout of ARVs, as discussed in section 6.1, one of the justifications brought by government was with regard to the drug's effectiveness in reducing the rate of HIV infection. However, the alternative perspective that has transpired asserts that ARVs do indeed reduce the transmission of the virus from mother to child. In addition, it has been argued that contrary to the claims presented above there is evidence that ARVs improve the quality of life of HIV infected people. Scientific and medical evidence on the effectiveness of the drugs in treating people with HIV comes predominantly from the industrialized countries like the US and Europe where since the advent of the use of triple combination ARV therapy in 1996/1997, their use has been shown to have impacted on the epidemic clearly. Fewer people get sick and more lived longer. In addition to such evidence, reference has been made to a study that was conducted in Uganda in 1999 which suggests that administering the Nevirapine drug to a pregnant woman at the onset of labor and to her newborn immediately after birth could result in a 50% reduction in the rate transmission of HIV (Annas et al cited in Berger et al, 2003:332). The case of Gauteng provides for another success story where Nevirapine has in three years saved nearly 58,000 newborn babies from contracting HIV/AIDS. Had the drug not been administered to more than 230,000 women in labour, authorities say, 30% of the babies born - that is 75,942 in total would have contracted HIV (Park, 2004). This was one basis for the claim that failure to provide the drug is a condemnation of access to these life-saving drugs to the tens of thousands

of newborns a year to HIV treatment in South Africa (Treatment Action Campaign, 2001).

The Treatment Action Campaign (TAC), which is among the major groups that have been advocating for a change within government policy so as to provide ARVs to pregnant women who give birth in the public health sector and to their babies, where the medical practitioner deemed this to be medically necessary. For the TAC, denial of access to these drugs is a human rights violation as people are deprived of their right to health care (ibid, 2001). For this reason it has on a number of occasions brought the Minister of Health to court urging it to provide antiretrovirals to pregnant HIV positive mothers treated at state hospitals, if the capacity existed and it was medically indicated (www.communitylawcentre.org.za, 2002).

In connection to this Justice Chris Botha of the Pretoria High Court underscored the ineluctable obligation of the state to provide a countrywide MTCT prevention programme. “Prohibiting the use of Nevirapine outside the pilot sites in the public health sector is not reasonable and … an unjustifiable barrier to the progressive realization of the right to health care.” He therefore ordered government to make Nevirapine available to pregnant women with HIV giving birth in the public sector, and to their babies (www.tac.org.za, 2003). Thus the High Court concurred that the government had violated section 27 of the South African Constitution in that the state had not taken reasonable measures within its available resources to provide women access to programmes that prevent HIV transmission from mother to child. This finally led to the Court ordering the government to provide a comprehensive national MTCT rollout plan by 31 March 2002 (ibid).

Also in July 2002, the Constitutional Court noted that the Constitution required the government “to devise and implement within its available resources a comprehensive and co-ordinated programme to realize progressively the rights of pregnant women and their newborn children to

have access to health services and to combat mother-to-child transmission of HIV" (Treatment Action Campaign, cited in Berger et al, 2003:54).

The TAC further demanded that government return to the negotiations of the National Economic Development and Labour Council (NEDLAC)[10] and make a commitment to signing a Framework Agreement with business, labour, and the community on a National HIV/AIDS Prevention and Treatment Plan (TAC E-Newsletter, 2003). However, instead of adhering such demands and court decisions, the Minister insisted on completing the trials around the effectiveness of the drug before its wider availability. This was however not welcomed by the Constitutional Court which asserted that: "A potentially life saving drug was on offer and where testing and counseling facilities were available it could have been administered within the available resources of the state without any known harm to mother and child". (Annas, et al, cited in Berger et al, 2003:336). This shows a violation of the government's constitutional obligation to take "reasonable legislative and other measures, within its available resources, to achieve the progressive realization" of the rights to "access to health care services including reproductive health care" (ibid).

The Court was explicit both in defining the human rights that were violated and in ordering a remedy. As to the rights, it declared that "Sections 27(1) and (2) of the Constitution required the government to devise and implement within its available resources a comprehensive and coordinated programme to realise progressively the rights of pregnant women and their newborn children to have access to heath services to combat MTCT of HIV." To implement this right, the Court ordered the government to take four specific actions:

[10] A body where government comes together with organized business, organized labour, and organized community groupings on a national level to discuss and try to reach consensus on issues of social and economic policy, called "social policy". Nedlac's aim is to make economic decision making more inclusive, to promote the goals of economic growth and social equity. (http://www.nedlac.org.za, 2004).

> -Remove the restrictions that prevented Nevirapine from being made available…at public hospitals and clinics that were not research and training sites.
> -Permit and facilitate the use of Nevirapine at public hospitals and clinics when … this was medically indicated….
> -Make provision if necessary for counselors based at public hospitals and clinics … to be trained for counseling….
> -Take reasonable measures to extend the testing and counseling facilities at hospitals and clinics throughout the public health sector to facilitate and expedite the use of Nevirapine (Annas et al, cited in Berger et al, 2003:336-337).

The issue/debate has also drawn the attention of some international organisations such as the Medicines San Fronteires (MSF) / Doctors without Borders. This organization has, in collaboration with the TAC, on many occasions shown its support for a policy geared towards treating HIV patients with ARVs. It has imported much less costly generic versions of ARVs into South Africa from Brazil, defying local patent laws. The organization administered the drug at different clinics, which has provided evidence, according to the group, that these drugs could indeed be used safely and effectively in South Africa (www.polity.org.za, 2001).

Although the TAC and MSF were accused of patent infringement, they have responded to such accusations by making reference to the South African Constitution which protects the rights to life and dignity. By importing these medicines, the two organizations believe that they have helped uphold these rights (www.tac.org.za/Q_A, 2003:1). In addition, according to the TAC,

> South Africa is a signatory to the WTO Trade and Related Aspects of Intellectual Property Rights (TRIPS) agreement,[11] which sets out the minimum standards of the intellectual property protection that countries must abide by. This agreement makes provision for compulsory licenses. Furthermore, in the 2000 meeting of WTO members in Doha, Quatar, it was agreed that TRIPS should not stand in the way of a country's health concerns (ibid, 5).

[11] International law agreement created by the WTO to protect intellectual property by granting patents for a minimum of 20 years for new inventions (eg. new HIV/AIDS drugs) (Barrett-Grant et al, 2001:467).

Before the Doha agreement, the TRIPS agreement had been used to try to prevent poor countries from importing cheaper generic alternatives where patented drugs existed. However, the Doha agreement stressed that governments have to consider the health of their populations by taking measures such as compulsory licensing[12] of medicines which are not in violation of the WTO's rules. In the Agreement, the Ministerial Conference of the WTO declared that the agreement on TRIPS should be interpreted so as to support public health and to allow for patents to be overridden if required to respond to emergencies such as the AIDS epidemic (UN, 2002:6).

Nevirapine's approval by the South African Medicine Control Council (MCC)[13], by the WHO, and the evidence from other countries in treating HIV patients effectively have further strengthened the point views brought by activist groups.

Trade unions have also gotten involved in the debate around the issue. As one of the groups that has opposed government policy on this and other issues, COSATU made it explicit that it did not doubt the link between HIV and AIDS. For COSATU, any other approach concerning the link between HIV & AIDS was "unscientific and, unfortunately, likely to confuse people. As a result, it can undermine the message that all South Africans must take precautions to avoid infection" (www.cosatu.org.za, 2003). The Union, moreover, has criticised some government authorities for politicising the issue and called for strategies to deal with the epidemic to tackle both the scientific and the social causes. It has also demanded that key authorities in government change their positions on the provision of ARVs and ensure access for those who need them. Finally it has questioned the stance that HIV may not be the only cause of AIDS and called on the concerned government authorities to change their positions accordingly (ibid).

[12] when a government issues a license to allow the production and selling of medicines (eg. ARVs) that are still under patent (Barrett-Grant et al, 2001:454).
[13] body with the duty of registering medicines when they are proved to be safe, effective and of good quality (Barrett-Grant et al, 2001:462).

Another group that has opposed some of the views presented by government (see above, section 6.1) is the South African Communist Party (SACP). Like COSATU, the SACP has not questioned the link between HIV and AIDS; it has called for a human rights-based and holistic response which dynamically linked prevention, care, access to information, management, awareness, support, access to social services and treatment. It has also backed up the struggle for affordable treatment (www.sacp.org.za, 2002).

Some critics have gone as far as describing the state's failure to meet HIV pregnant women's right to adequate health care services as tantamount to sentencing innocent people to death. Dr. Gazi, health secretary of the Pan Africanist Congress and Thomas Coates, from the University of California AIDS Research Institute, are among those who have described as *genocidal* the failure to treat HIV pregnancies in South Africa with antiretrovirals (Bond, 2002:181). From this perspective the state's failure to provide a wider treatment programme to HIV positive pregnant women with ARVs is not just a violation of the socio-economic right to health but a violation of one of the most fundamental human rights, that is the right to life. In addition, it implies a failure to fulfill the duty imposed on the state by the Constitution in section 7(2) (1996:6), which mentions, the duty of the state to respect, protect, promote and fulfill the rights that are enshrined in the Bill of Rights.

Finally, several provinces have begun administering Nevirapine to, *inter alia*, HIV positive pregnant mothers under their administrations, viz. the Eastern Cape, KwaZulu Natal, Gauteng, and Western Cape. These decisions put the provinces at odds with the National Minister of Health who wanted the provinces to refrain from using the drug until trials were completed on their toxicity, thus implying the need for the Minister to respond to HIV/AIDS with antiretroviral drugs and thus posing a major challenge from within the government to the Minister who had expected their conformity in this regard. The position of these provinces has further

raised suspicion that the alleged need for completion of the said trials before the drug's wider availability represents a delaying tactic and is tantamount to gambling with the lives of millions of citizens who could not afford to buy the drug (Blaine, 2002).

One of the main reasons for the change of heart of key position holders in government is probably that new and cheaper medicines have become available, and there are new opportunities to manufacture these drugs in South Africa (Alfreds and Jacobson, 2003:4). However, it seems safe to conclude that it has also been the result of the above raised internal and external pressures that have emanated from, *inter alia,* activist groups, court rulings, trade unions, political parties, as well as from the unilateral decision taken by various provincial governments to rollout the drugs, that the national government at last decided to implement a national comprehensive treatment programme. This was officially disclosed when the Deputy President Jacob Zuma openly stated that "the government will introduce an antiretroviral programme as soon as possible" (Deane, 2003). Accordingly, the government made a pledge to provide ARVs and the Cabinet announced on August 06/2003 that South Africa's first generic drugs, up to 14% cheaper than the original, were to be manufactured. The drug, Aspen-Stavudine, costs less than $1 (about R7) a day. The manufacturer of the drug, Aspen Pharmacare, has applied to the Medicines Control Council (MCC) to be allowed to also manufacture generics of other ARVs such as AZT and Nevirapine, which has been welcomed by the Cabinet (Clarke, 2003).

It has been a positive development to see a consistent position eventually evolve within the government including those who have for long denied the effectiveness of ARVs. The Minister of Health, who has denied about the effectiveness of the same drugs for years, deserves a special mention. At once she was reported to have denied the effectiveness of ARVs in treating HIV positives by urging the media to help her Department with "the promotion of health and nutrition and to encourage people to grow vegetable gardens - garlic, onions, olive tree, and the African potato as key

elements in the fight against AIDS and other diseases. She has also requested the MCC to do further studies on the African potato, which she said had achieved 'astonishing results' in curing disease" (Batterby, 2003:3). Contrary to this stance, she finally, in August 2003, publicly conceded that "ARVs can help improve the condition of people living with AIDS when administered at certain stages, in accordance with international standards. Appropriate support systems and a caring environment are critical for its success, and our Constitution dictates that health services should be accessible to all. We must all ensure that in spite of the magnitude of the problem, human rights are respected" (Terrenblanche, 2003:1).

The decision to finally treat AIDS with ARVs is what many individuals and groups within and outside government have been calling for. This shows us how such groups successfully challenged some positions within the state by employing human rights discourses as one of their strategies. Advocacy of such rights has been an integral mechanism in forcing and assuring the protection of human rights in a situation where state action had threatened them. Thus, the employment of human rights discourses together with the strategy of advocacy had major relevance for shaping a homogenous and appropriate response as far as the provision of ARVs in South Africa is concerned. The change in position within the national government's key authorities in the provision of ARVs is therefore a manifestation of the success of those groups who worked in favour of treating AIDS patients with ARVs.

The success, however, did not stay longer. Accordingly, the national ARV rollout programme was later suspended because, according to Dr. Nono Simelela, former Head of the HIV Unit at the Department of Health, "demand for the ARVs far outstripped supply". This action was disputed by the TAC and the National Association of Pharmaceutical Manufacturers who claimed that the pharmaceutical companies have sufficient stock and that such excuses placed the lives of people living with HIV at risk (Sefara, 2004).

From engaging with the most prominent arguments against a comprehensive national rollout of ARV treatment for HIV positive pregnant mothers, the following impression is generated. There seems to be - on the side of key position holders in government - a superficial commitment to human rights. However, this commitment appears to be somewhat overridden by ideological positions, such as, for example, by what impresses as a deep seated suspicion of 'Western' medicines. Such suspicion might in turn be motivated by the - to all intends and purposes justifiable - suspicion against the motives of those companies that are producing, marketing and benefiting from the sales of such medicines.

However, this suspicion oddly combines with a seemingly uncritical adoption of 'Western' economic orthodoxy. As a result, the said concern for human rights appears to become conditional on economic considerations, which in turn are framed within a neoliberal interpretation. The resultant conclusion that a comprehensive ARV rollout is unaffordable in the South African context, however, makes sense only from within such a neoliberal frame of reference, where minimal social spending is one of the most important pillars of sound economic policy.

The complexity of the issue is exacerbated by the fact that such considerations are not expressed explicitly. Instead, some of the arguments that have been employed to legitimize government inaction with regard to the said rollout of drugs engage with a human rights discourse, however, re-interpreting it fundamentally. This has been done by creating binary opposites (eg. right to clean water vs right of access to ARVs) which impresses as logical on the surface, but cannot be sustained when interrogated critically.

A review of the processes and arguments that have eventually led to an apparent shift in key government positions demonstrates that it is possible - by employing human rights-based public discourse and litigation - to impact

existing power relations and to influence dominant discourses for the benefit of disadvantaged members of society - here, HIV positive pregnant women. While the use of strategies such as conscientisation and social action has been referred to rather implicitly, the following chapter will investigate these positions and processes further. The facts that universal ARV rollout to HIV positive pregnant women is not yet a reality, and that new obstacles have emerged even in the process of conducting this research, demonstrate that social change is but an ongoing process and does not necessarily constitute a linear form of progress.

CHAPTER SEVEN
PRESENTATION OF RESEARCH FINDINGS

The previous chapters have provided a general overview of the HIV/AIDS epidemic that is its history globally and in South Africa, modes of transmission, prevention, treatment and cure; broader issues around human rights in relation to their link to public health and the Social Work discipline as well as the debate that has surrounded the universal supply of ARVs to HIV positive pregnant women and their newborn babies. The focus shall now be on data presentation and analysis**.** The data was collected from a purposive sample of interviewees from organizations representing a cross section of views on the subject matter. Semi-structured interviews were conducted between January and June 2004 with representatives from the National and the Gauteng Departments of Health, the Treatment Action Campaign (TAC), the Wits AIDS Law Project (WALP) and the Chris Hani Baragwanath Hospital Perinatal Research Unit. The interview guides were structured according to themes that had emerged from a preliminary literature review. Following the data collection and its subjection to a threefold coding process (that is, open, axial and selective coding), further trends and differences were identified and the original themes were refined accordingly. The research findings are therefore presented in the following order:

-The barriers that prevented the government from implementing a countrywide ARV rollout programme;
-The issue of human rights in the context of the provision of ARVs;
-The provision of ARVs in the context of the current global market economy and its impact on inequality; and lastly,
-Different factors that have led the government to make a change in its long-standing position with regard to national ARV rollout programme.

Before presenting the actual findings, it is worth mentioning certain difficulties that were experienced in the actual process of data gathering. The very difficulty was the reluctance of government officials from the Department of Health to respond to my e-mails and telephonic requests to set a specific time for an interview. Despite more than ten e-mails and about twenty telephone calls to four officials over a period of four months, none of them sat for an interview. After all these delays, eventually, two interviews were granted, one face-to-face (with a representative from the Gauteng Department of Health) and the other electronically via e-mail (with the National Department of Health). Both responses were extremely brief and limited in scope as compared to the interviews held with the NGO representatives. All in all, the impression generated was that the government officials approached in the course of this study were reluctant to engage with the complex of human rights, HIV/AIDS and the discussion around antiretroviral drugs.

7.1 ARGUMENTATIVE BARRIERS AGAINST THE PROVISION OF ARVs

As discussed in Chapter Three, since the discovery of ARVs, many countries have made them available in their health centers and have shown a significant reduction in the number of their HIV/AIDS cases. However, in South Africa, due to various barriers discussed above (see section 6.1), the government has not yet made these life-prolonging drugs comprehensively available in public health centers. With the intention of developing a thorough insight into these barriers, this section will begin by presenting responses relating to the issue of capacity of the health care system as well as the price of medicines, followed by responses pertaining to the issue of political will. These three sets of data will be discussed against each other and against some of the findings from the literature review before a final interpretation is provided.

All respondents at some points of the interviews made reference to the complexity of managing ARVs, the capacity of the South African health care system and the cost of providing the drugs. For example, according to the interviewee from the provincial Department of Health,

> the price of the drugs, the infrastructure, and the health system, which was not ready, made it impossible to provide the drugs. Even now as we are trying to implement the programme, there are huge challenges out there. People are only now realizing that it is actually not just easy- you cannot drop a bucket of drugs at a clinic and say give it to the people. There is a whole lot of things that you need to prepare the system, the communities, to make sure that the victims have a constant supply of the drugs and that they do not get super infected whilst they are on drugs.

This confirms what has already been noted in Chapter Six that is, the capacity of the South African health services which is believed to be not as strong as it should, a system that has not yet been fully transformed. However, an activist from the TAC elaborated on the mismanagement / underspending of the AIDS budget when he made reference to a provincial MEC who was accused of squandering the province's budget due to the lack of proper oversight and control being exercised at national level. Thus, he concluded that the alleged lack of capacity and lack of transformation "cannot be a justification for the delay because South Africa has one of the most advanced public health systems in Africa certainly and the effect of not preventing the epidemic undermines the health service because what happens is that the beds in hospitals, in pediatric wards, and so on will end up being crowded by people with AIDS." The interviewee from the Wits AIDS Law Project (WALP) substantiated this by giving evidence in the following manner "….in the government's plan it is estimated that the number of hospital visits has increased by 100,000 per year over the last few years, a lot of which has to do with HIV infections." In other words, the government's lack of commitment to rollout ARVs in general and to HIV positive pregnant women and their newborn babies in particular contributes to increasing

rates of opportunistic infections and subsequent deaths amongst already infected adults and children who should have been prevented from being infected in the first place. This, by implication, must lead to the progressive mismanagement of capital and other resources.

The other barrier has been, according to the respondent from the National Department of Health, around the affordability of the drugs. Yet according to the activist from the TAC, while this might be an issue in other countries, this seems not to be a real problem in South Africa because it is not a poor country. That is why even in the Constitutional Court case, instead of producing the argument of cost, what government presented as a major impediment to the actual implementation of the programme was infrastructural concern. This is largely because the price to the general public has been reduced dramatically in the last five years. He substantiated this claim by saying, "…in the year 2000 it would cost about R5,000 a month for one person to take the drugs. However, as was negotiated at the end of 2003 we are now looking at prices of about R300 per month per person and sometimes even lower than that." In addition, the interviewee from WALP reported that in the South African private health care sector, there are presently about 20,000 people on ARV treatment through medical schemes and claimed that there was documented evidence that the cost of hospitalization in respect of this group had gone down. He stated that as a result, the pattern of health related spending had changed as there was more money being spent on medicines but less on hospitalisation.

Furthermore, the same respondent added that "the collection of tax is better now than it has ever been before. The revenue raised by the Revenue Service every year has increased so that over the last few years there have been major tax cuts for individuals. It is therefore, unlikely for South Africa to make the argument of non-affording the programme". Instead, in relation to both treatment and prevention, the implementation will cost the state much less than not to implement it. "The implementation of a public sector MTCT programme would involve

the commitment of substantial resources, estimated at 0.5% of South Africa's annual health care budget. However, it may actually save money, given the high costs of treating children born with HIV under the already existing programme of providing free care to those children under five in need of such care."

Over and above the purchase price of the drug itself the government official from the National Department of Health found that the issue of breastfeeding versus formula feeding compounded the cost factor further. She explained that "the cost of formula feeding for women who choose not to exclusively breastfeed takes between 40-50% of the Department's budget, which has to be seen with the safety profile of medications such as Nevirapine. This also impeded the implementation of the programme". Another respondent from the TAC noted regarding the nature of controversy around the issue of breastfeeding - that government was over-emphasising the issue at the expense of the overall health of pregnant women living with HIV. His interpretation was that in the face of the epidemic's great threat and the high demand for ARVs, this amounted to finding excuses rather than expressing real concerns. Such an assertion resonates with the findings from the literature review that some of the arguments against a universal ARV provision ignore the complimentary nature of socio-economic rights (see above, section 5.1) and instead treat them as though right was only realizable at the expense of another.

Likewise, the following comment from the interviewee from Chris Hani Baragwanath Hospital suggests that more might be at stake than just the question of affordability and feasibility of providing ARVs to HIV positive pregnant women "…..every time the government opens its mouth about ARVs, it tells us how difficult it is, the obstacles, the toxicity / side effects, the infrastructure, etc and it never ever says this intervention will save lives. Of course, it is hard, it is difficult, it is going to be a challenge but it can save lives." This comment insinuates what was more openly expressed by the TAC activist who noted that "the biggest barrier has

been the political will of the government to commit to a treatment programme that uses ARVs which has its roots in opposition by the President and the Minister of Health, based on mistaken beliefs about the toxicity and suitability of these drugs." In addition, the activist referred as politically driven to the public messages by the Minister of Health that ARVs were poisonous. Messages such as that which recommended the use of the African potato and garlic for treating HIV positive people (see above p.73) have according to the respondent from WALP, been based on

> ……the resistance that exists to using ARV drugs on the notion that ARVs are Western medicines, that they do not work and that what is happening is that the big multinational pharmaceutical companies are trying to create a market for these medicines in poor countries to make profit. Contrary to the Minister's position, the issue is not that whether you have ARVs or nutrition- the question is that people need good nutrition and ARVs when they get sick. So the two things go side by side with each other. Unfortunately, the Minister of Health in this country is acting in a very dangerous way because she is giving wrong information about nutrition. The African potato does not universally improve a person's immune system, and what we really need is accurate information about diet/nutrition. So she is confusing its use very badly and violating people's right to full and accurate information, which is a constitutional duty of the government.

In other words, there is a suggestion not only that government lacks political will but also that this lack of will is based on an ideological[14] bias against non-African remedies to HIV/AIDS. Such a notion is refuted by the respondent from the provincial Department of Health who emphasised the government's maximum efforts in making ARVs affordable, accessible and available in the country, albeit without backing this assertion up with empirical evidence.

[14] a system of ideas or way of thinking pertaining to a class or individual especially as a basis of some economic or political theory or system, regarded as justifying actions and especially to be maintained irrespective of events (The New Shorter Oxford Dictionary, 1993:1305).

In interpreting the various responses on the barriers against the provision of ARVs to HIV positive pregnant women, it is important to separate objective difficulties from the apparent lack of political will to overcome these difficulties. As has been noted, the capacity of the health service is not as strong as it should be which needs transformation. It has also been noted that the provision of an ARV treatment regimen is complex as it requires people to take medication everyday for the rest of their lives in addition to the demands on the public health sector regarding administration, training, strengthening of service points, strengthening laboratory testing capabilities, etc. However, while these arguments are often conflated, it is important to distinguish between calls for the once-off provision of ARVs to HIV positive pregnant women on giving birth and calls for the life-long provision of ARVs to all persons suffering from AIDS. The demands both on patients and on the capacity of the public health sector posed by the two programs are vastly different, and the said argument hold much less for the former program than for the latter.

In addition, these factual difficulties need to be interpreted against budgetary incongruencies such as the South African government's R40 billion spent on re-armament in the absence of any military threat (Heywood, 2002:220-221) while it is argued simultaneously that there is a lack of resources to expand access to HIV counseling, testing and provision of ARVs. This may be interpreted as being tantamount to bad economics, a point which both respondents from the Department of Health failed to comment on and which will be discussed below (see section 7.3).

From the discussions of the presented data against the reviewed literature, it appears therefore that arguments against the provision of ARVs lack adequate economic bases. Generally, while ARV treatment of large numbers of people may be complex, has risks associated with it in certain respects, and has been expensive in the past, there appears to be little dispute outside the South African government about the cost-

effectiveness and efficacy of the drugs. Consequently, it appears that the respondents representing the NGO sector in the sample are justified in identifying a lack of political will as preventing the South African government, through its Department of Health, from tackling the factual barriers it finds in the current health system, including the costs of ARVs, in a decisive manner.

7.2 HUMAN RIGHTS DISCOURSES AROUND THE PROVISION OF ARVs

As generally discussed in Chapters Four and Five, human rights are a crucial reference point for the protection and promotion of the right to access to health care services. In order to explore in detail how human rights arguments have been employed in enforcing the implementation of a national ARV rollout programme for HIV positive pregnant women and their newborn babies, this section will discuss the responses of all participants regarding the different legal mechanisms, the government's constitutional duties, the Constitutional Court orders/decisions, and the role of human rights discourses that were employed by activist groups. These data will be discussed against each other and against the findings from the literature review in order to arrive at an appropriate interpretation.

As part of the right to access to health care services, according to the TAC activist, the National Treatment Plan of the South African government recognizes the government's constitutional obligation to guarantee everyone the right to access to health care services, a right that must be achieved progressively according to available resources (The Constitution of the Republic of South Africa, Sections 27(1) (a) and 27(2)). The government official from the National Department of Health, however, stressed that "reasonable legislative and other measures" within "available resources" to achieve the "progressive realization" of this right (ibid) had to be based on epidemiological evidence and take into consideration as well as address the health concerns of the whole

population. Likewise, the official from the Gauteng Department of Health claimed that "we do not see the provision of ARV rollout programme as an isolated intervention from the provision of the overall health care services in the whole country- it is part of a comprehensive management as a prevention strategy in reducing transmission of HIV from mothers to babies but that needs to be seen in the context of the whole national strategic framework of prevention strategies." Such arguments maybe interpreted as implying that the provision of ARVs to HIV positive pregnant women and their babies is not a priority and thus, according to the TAC activist, "undermining any sense of urgency in this regard." They then undermine in turn the July 2002 judgment of the Constitutional Court in the case of the TAC vs the Minister of Health which instructed the South African government to make the medicine Nevirapine available on progressively expanded bases, he explianed further.

Yet, the official from the Gauteng Department of Health stated that

> The government has gone a long way in providing health care services to all pregnant women - not only HIV positive - but *gone an extra mile* in reducing transmission from pregnant mothers to their children. And it is not only the care/the reduction of the transmission itself, it is also about caring for women who are found to be HIV positive during pregnancy which includes things like providing post-exposure prophylaxis[15], treating opportunistic infections and providing nutrition etc. So all of that has been happening, and to that degree I would say that they (that is the right of pregnant women to access health care services) have been met (italics and brackets mine).

Effectively supporting the views expressed in this comment, the official from the National Department asserted that

[15] taking antiretroviral therapy within 72 hours after being exposed to HIV, eg. after rape (Barrett-Grant et al, 2001:464).

> …..HIV positive pregnant women are given Nevaripine to reduce chances of HIV transmission to the unborn baby, thus protecting a right to life. *They* receive pre and post-test confidential counseling and thus respect their right to dignity. *They* also receive psychological support to deal with the consequences of being positive; they are given STI, TB and other opportunistic infection treatment. *They* are also referred to other services to ensure that they are able to cope with their status (highlights, mine).

The insinuation of these two claims is that the constitutional right to access to health care services held by HIV pregnant women and their new babies at large were indeed adequately met. However, this notion contradicts the lack of budgetary and institutional capacity alleged by the same respondents at other points. It also contradicts the literature review's findings that the rollout of ARVs is to date not a reality. Instead, it must be stressed that the South African government, rather than fully meeting its duties, is meeting them in a haphazard way in, thereby exacerbating existing inequalities between regions and between social strata (see below, p.95). According to the TAC activist,

> ….government was meeting its duties in some provinces but not in other provinces. If one looks for example at Gauteng, there was broad access to ARVs to prevent MTCT but not in Limpopo or Mpumalanga where there are still many clinics that do not offer counseling services and treatment. And that led the TAC to in fact start a new legal case against the MEC for Health in Mpumalanga, a case that was never finalized because after the TAC issued the court papers, the Mpumalanga government moved quickly to try to get drugs into the relevant places and to start build services.

This kind of implementation of the rollout programme is a clear indication of policy inconsistency.

When challenging such a government stand and opening court case against the Minister of Health, the TAC's legal basis for litigation was first and foremost the duty to progressively realize peoples' rights of

access to health care services (that is section 27 of the South African Constitution). However, a number of legal arguments with regard to other human rights, that is, dignity, equality, children's rights, rights to make choices regarding reproduction, which fall under freedom and security of the person, etc were made in support of this section. Generally, according to the TAC activist, "we have always based our arguments on the discourse of human rights and public health approach from the first day of the TAC."

He further emphasized that "in our argument, we would not say that there is a human right to ARV treatment … because [there] is not just an absolute right to medical treatment but there is a right of access to health care services combined with right to dignity, right to life and the combination of those rights instructs government in terms of how it should conduct itself." But "we would not certainly say there is a human right to ARV treatment because at the end of the day if we say that, then we would effectively be saying that people who do not need treatment have a right to treatment." All in all, the legal arguments have always been based on sound legal and ethical grounds in demanding the provision of the drugs at facilities where there is capacity to provide and extend them and build that capacity over time, the TAC respondent noted.

In support of a countrywide ARV rollout programme, the TAC activist made reference to the use of strategies beyond court action. He reported that "….we have literally written hundreds of memoranda to government in the last five years demanding the government to make the drugs available in the public health sector." In addition, he made reference to strategies such as "the use of economic arguments, research, mobilizing people within communities, building support among health care workers, etc. Again when going to court, all the other activities do not stop. By so doing, other activities are encouraged; media attention on the issue is brought, etc". Thus, the Constitutional Court order that government implement a countrywide ARV rollout

programme, and alleged delays in government's compliance subsequent to the issuing of this order were embedded in a context of awareness raising, organizing, social action with a view to influencing public opinion in support of this order - all of which are strategies and approaches available to civil society organizations and form part of the Social Work skills and knowledge base (see above, section 5.3)

The interviewee from the National Department of Health however, denounced claims that it was delaying in its compliance with the said Court order, by saying,

> The government has not failed to implement any Constitutional Court order because it respects the Court. The government is the bearer of rights as enshrined in the Constitution. It will be very naïve for anyone to reject Constitutional Court decisions reached in the spirit of the country's Constitution; there is no basis for that in our judicial system. However, you should also bear in mind that the government as any other citizen of this country, has the right to appeal against a court judgment in a litigation it was involved, if it has sufficient reasons to believe that the court did not take into consideration some facts or it did not put necessary emphasis on some facts or there is new evidence or facts available which could have otherwise influenced the judgment of the *court a quo* if were presented.

The assertion of a well-intended government eager to comply with the said Constitutional Court order but unable to do so for reasons insufficiently understood or acknowledged by the Court was refuted by the interviewee from WALP who disclosed that

> the government did not have any legal basis [for an appeal against the said order]. It might have a basis for disputing what the judgment action said and what was required. The main argument that it tried to make was that the Court had overstepped its powers; that basically it had intruded in the power of the executive/of the Cabinet, the principle of separation of powers which the government claimed the Court

> failed to recognize. However, the Constitutional Court rejected such an argument by saying that its purpose is to watch the executive on how it uses its powers. The government even went further to bring other arguments such as the side effects of the drug- that they were not proven, that there was a possibility that they might be deregistered. Even such arguments were really red herrings and destructions and the Court was clever enough because it had the papers and the legal evidences not to be misled by such things. As a result, those issues did not really weigh heavily in the judgment (brackets, mine).

A further source of complexity is that when it comes to forcing the government to abide by its rulings, the power of the courts is limited. The interviewee from WALP noted that the constitutional contracts of South Africa include is the acceptance of the supremacy of the Constitution, the acceptance of the power of the executive and the legislature, as well as the requirement that all laws must be constitutional, all of which have implications with respect to the Constitutional Court's work. Thus, the system's design is based on the presumption that once the Court instructs government to change a policy or a law, the latter will abide by that instruction. If it fails to do that properly, "one can bring another application for contempt of court and take the government back to court to try and seek a variation of the order [and] get another judgment which is even stricter in terms of what government must do", said the interviewee from WALP. In the context of the court case on the universal rollout of ARVs to HIV positive pregnant mothers and their babies, it is important to note that

> the order of the Court which gave effect to say that we do not expect you (that is government) to implement everything immediately but the question is whether government is doing enough, taking sufficient steps to make sure that over a period of time everyone gets access to treatment, which I do not believe it is. But it is very difficult to prove the developments because [one] cannot get anyone to testify to that effect, the activist elaborated further.

"But historically", the TAC interviewee remarked, "our Constitutional Court has not been keen to do that because it is conscious that it is a court, it is not an elected government. So while it has to judge from time to time on government policy, its job is not to take over the functions of the government. That is the problem with legal enforcement generally: … if government is ordered to do something that it does not want to do then it will carry out that order in a fashion that is half-hearted, sometimes slow….." It is therefore that the leverage to get court orders enforced lies predominantly outside of the Court which has more to do with "monitoring, political will, mobilization, embarrassing the government, bringing things to the attention of the media, etc" the same activist further explained.

When reviewing the above data against the literature, it appears that government's delays in rolling out ARVs to HIV positive pregnant women and their babies have been in contravention of the principles contained in the Constitution and other international documents the country is signatory (see Chapter Four), such as the right to dignity, life, equality, access to health care services and special protection of children, etc. which create duties on the government. In pressurizing the state to implement the Constitutional Court's decision, the Court is constrained by its limited power. Here it is important to note that the slow implementation of the rollout programme in some parts of the country may not necessarily mean that it was a violation of the Court's order but it is. Ultimately, the question of whether government has complied with the said order or not is a matter of interpretations, and thus, very difficult to prove.

Government's delay to rollout ARVs has been based partly on the notion that there is no direct right to ARV treatment. But according to several of the research participants, such a right can be derived from a combination of civil, political and socio-economic rights. In other words, the dispute between government and civil society organizations has been based on different interpretations of the claim to human rights of

ordinary people, here, HIV positive pregnant women and their babies. In view of competing legal interpretations of human rights and in view of the limited power of the court system, it has been necessary for civil society organizations to mobilize and to continuously and publicly pressurize government to implement the said rollout programme. Thus, the data analysis allows for a sharper formulation of what has already been implied in the literature review: For a litigation process to unfold its full potential, it depends on the ability of civil society to engage in social action around those human rights and other discourses relevant to the court case concerned. It may have been that the cumulative effect of the various strategies employed in this particular instance was - while the *legal dispute* continues - that government's *moral legitimacy* and its claims to the *economic rationality* of its inaction became progressively eroded as the delays of a universal ARV rollout continued. In other words, in view of government's already documented attempts to use its power to frame human rights discourses in such a way as to legitimize its lack of action, it was of extreme importance that the legal dispute was complemented by economic, rights-based, and ultimately moral, discourses.

7.3 THE PROVISION OF ARVs IN THE CONTEXT OF THE CURRENT GLOBAL MARKET ECONOMY: IMPACT ON INEQUALITY IN SOUTH AFRICA

As discussed in the previous sub sections of this chapter and in the literature review (see section 6.1), one of the main arguments produced by the South African government justifying the delays in implementing the ARV rollout programme has been the issue of the high cost of the drugs and the abuse of patent laws by few pharmaceutical companies, both arguments which are related to the nature of the current global market economy. In turn, the socio-economic effects of the delays in the ARV rollout have been profound and must therefore form part and parcel of an economic discourse on the subject matter.

To develop a deeper insight into the discussion around the universal supply of ARVs in the current market economy, this section will begin by presenting responses relating to the role of civil society organizations in challenging existing patent laws and lobbying for the reduction of the high cost of the drugs**.** This will be followed by a discussion of some of the socio-economic implications of the delay in implementing rollout programme in the country. This set of data is going to be discussed against each other and against the literature already reviewed before interpretations are provided.

Patent laws[16] were among those widely quoted causes/bottlenecks in implementing the rollout programme. However, according to the TAC activist, legally and ethically patent laws should not be abused by companies to set prices that make medicines unaffordable. Africa as a whole is a case in point where large portions of the global burden of diseases such as AIDS, malaria, TB, cholera, etc have deep roots. This led the activist to argue, "certain types of diseases have been globalised. The tragedy, however, is that while there has been a globalisation of medical research and knowledge about medicine, there has been only a partial globalisation in their availability." With a disproportionately high share of the burden of many diseases, the continent constitutes only a tiny fraction of the global market for medicines. Such a disjuncture between the high presence of diseases and the limited use of medicines, he explained, can be largely attributed to "the high cost of medicines and to the lack of appropriate investment in health care services". However, such bottlenecks can be challenged by, according to the respondent from the TAC, the actions of vibrant civil society organizations as demonstrated by our organization [the TAC] - that is,

> …..we took the pharmaceutical companies to the Competition Commission[17] in South Africa and

[16] The legal protection of products (eg. antiretroviral drugs), which makes it unlawful for someone else to copy, manufacture, import and use the product without the patent-holder's permission (Barrett-Grant et al, 2001:463).

[17] In terms of the Competition Act of 1998, the Competition Commission seeks to provide all

> complained that they were abusing their patent, the monopoly given to them by the patents to set prices that had no relation to the actual economic value of the medicine. So the Commission found that there was evidence supporting our allegations, and that forced the companies to reach a settlement with us and in so doing, they have agreed to license generic companies to make the drugs, to use their intellectual property. So although the issue of patents is a barrier, it is not an insurmountable barrier. It is a barrier that can be overcome.

With the same objective in mind, that is, to overcome the barrier created by the current global market economy, the official from the National Department of Health commented on the role of human rights discourses by stating that

> a human rights-based approach entails that the existing resources be shared. Non-availability of resources to realise a human right may mean that somebody has not carried out her or his duty in the generation, management or protection of that resource. The human rights standard regarding the use of resources is that appropriate measures must be adopted. The realisation of human rights must remain challenges in that attained goals must not merely be sustained but progressively be made more ambitious. Whilst human rights cannot be prioritised, scarcity of resources and institutional constraints demand that actions to realize rights must be prioritised. This often means policy choices. In this regard *a human rights approach/perspective does not help* in such choices. This is where *a human development approach* becomes *more useful*; its analysis helps us to see these choices in explicit and direct terms (italics mine).

In the current global market economy which is characterized by the apparent power of a few global drug companies which in turn operate

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South Africans with an equal opportunity to participate fairly in the national economy, in order to promote a more effective and efficient economy. The Commission is responsible for investigating complaints made against firms engaging in restrictive business practices, and for evaluating, approving or prohibiting mergers and acquisitions. In addition, the Commission conducts research, provides policy inputs, educates and informs stakeholders, and conducts regulatory and legislative reviews (www.compcom.co.za, 2004).

according to the notion of 'profit before people', ensuring an appropriate supply of ARVs at an affordable price remains a huge challenge. This challenge could be overcome, according to the same official from the Department of Health, partly through the use of legislative power. To complement this,

> NGOs and the civil society have a role to play in lobbying for the reduction of prices and to mobilise resources to ensure the sustainability of programmes such as ARV rollout. In so doing, NGOs, as well as being accountable to donors, must be accountable to the civilian population whose rights they are seeking to protect.

Here it is worth mentioning that in order to effectively lobby for the reduction of medicine prices, NGOs need the necessary cooperation of national governments. However, while government has so far argued that the use of ARVs is expensive and complex, it has, according to the TAC activist, failed at the same time to take the necessary steps to reduce the prices of the drugs (for example, it did not use its powers to issue compulsory licenses that would have reduced the price of the drugs). Thus, the respondent concluded that "the focus [should be on the question] why government is not actually taking the action that it could take to bring the drug prices down when it has the power to do that" (brackets mine).

It is striking that in the context of the *costs* of antiretroviral drugs, the respondent from the National Department of Health contended that human rights and human development were contradictory concepts. This claim is of particular concern in view of the assertions by one of the NGO representatives; that is, government failed to use its available power to keep drug prices in check. So it may be argued that a greater concern for human rights might have prompted government to do exactly that, which would allow for the conclusion that human rights and human development are indeed complementary notions. Therefore, in line with the arguments presented above on the complementary nature of human

rights and public health, it stands to reason that it is precisely a focus on human rights that would be able to give direction and impetus to a human development-based approach to public health. In that way, the claim to an alleged contradiction of concepts - while it may well be argued that they are in fact complementary - repeats a theme already established, that is a manipulation of the human rights discourse so as to legitimize government inaction.

This discussion leads us to implications of such a government action on inequality. Obviously, it has huge negative impact when seen in light of social justice and against the country's Constitution, which ensures the equality of people. However, people are not equal if they do not have enough money to buy medicine which exacerbates people's level of inequality because, according to a TAC activist, "those with enough money do not have to rely on government programme as through the coverage of their medical scheme they could get access to treatment". That is a deepening of existing inequality, which undermines the intentions of the Constitution, that is, to narrow down the inequalities in the country.

Thus, the interviewee from the TAC remarked that, since democracy, and contrary to the intention of the government, the gap between the rich and the poor with regard to the quality of health care services has become wider." This is further exacerbated by the action of the government which is distributing ARV drugs for those who are on government medical aid scheme, a claim which has led the same interviewee to give his witness in the following manner: "I know government officials, senior ANC members of parliament, a judge, etc who get the medicines. That is an inequality and injustice because these officials are believed to be at the forefront to look after the lives of the people who voted for them, and their constituencies."

Such disparities in accessing treatment clearly contribute to poverty. The interviewee from WALP substantiated this by stating that "if poor people

cannot get treatment, they are most likely to get poorer because instead of being able to get free treatment through a government programme, they spend what little money they have on trying to self-fund treatment." Therefore, contrary to what the government said, the issue around HIV is not that we have to deal with poverty first, instead, "we have to deal with the disease and poverty simultaneously because if we do not deal with them parallel, HIV will worsen poverty and then by doing so poverty worsens HIV. It is therefore a kind of vicious circle where inequality affects health and ill-health creates new inequality in the country", the WALP interviewee further elaborated.

Asked about the implications of government's delays in starting a countrywide ARV rollout programme for inequality, the government official from the Gauteng Department of Health defended government by saying:

> With regard to inequality that does not only apply to the management of HIV, it really applies to *everything*. However, you can never in the history of this country find any other government that [has worked in] the interest of *the* people. You can never! This is a government that has gone *out of its way* for the interest of *the* people. It has made health care freely accessible to all, but that is limited by whatever resources are available. (italics mine)

In interpreting the above responses, it is important to note that the price of ARV drugs such as Nevirapine has now been brought down considerably, and a number of companies - as a result of bold efforts made by organizations like the TAC - have been licensed to produce generic equivalents for the prevention of MTCT. Therefore, as discussed above, the provision of ARVs is now relatively affordable (see above, section 7.1). In addition, it has been noted in the same chapter that other middle-income countries are treating their patients with ARVs. Thus, the South African government should take appropriate advantage of the space created to curb emerging further inequalities.

Yet, the respondent cited here did not engage with the rather tangible question of whether or not, or in how far, the South African government's stance and inaction with regard to a universal rollout of ARVs has exacerbated inequality in the country. Instead, the respondent evaded the issue by making broad and generalized claims to the government's overall efforts on behalf of the people at large. This is in spite of the fact that the complex of price setting by international drug companies would be an ideal opportunity to explore rather than resist the possibility of creatively combining government's particular leverage with the strategies and approaches unique to civil society organizations. Purpose being one which government and civil society should be easily able to rally around, be it from a human rights, social justice of human development perspective, that is, to roll back the power of the pharmaceutical companies - for the benefit of one of the most disadvantaged groups in South African society, that is HIV positive pregnant women and their newborn babies.

7.4 PROCESSES LEADING FOR CHANGE IN POSITION OF THE SOUTH AFRICAN GOVERNMENT

In spite of the various barriers and arguments presented in the above three sections, it has already been noted that national government, following long delays in agreeing to implement a countrywide ARV treatment programme for HIV positive pregnant women on giving birth, has recently changed its long standing position. This section therefore engages with the participants' responses pertaining to the various factors that have led to this end such as the drop in the price of the drugs, local and international public pressure (including litigation), lobbying, the huge socio-economic impact of the epidemic and resultant government pragmatism.

According to the official from the Provincial Department of Health, government eventually committed to making the said drugs available

countrywide as it was encouraged by the body of evidence and knowledge emanating from the consultative forum which had been instituted at national level in the area. In addition, in order to assess the effectiveness of the drugs, an independent institution (Health Systems Trust) had been asked to conduct it in the 18 pilot sites which showed a positive and encouraging result. The official's argument was, however, disputed by the TAC activist who made reference to a National Health Summit of November 2001 that was organized by the government which took a resolution on piloting the use of ARV treatment but "there had not been any sites run by the government on the use of these medicines - government tried to do it to prevent MTCT but not as treatment. That was the issue that led our organization to tell the government that there is no need for pilot sites because the fact that the medicine works was already established and it accepted that as it was unlawful to limit access to medicines to a few people in pilot sites when there were many other sites around the country which would have the capacity to provide treatment", the activist disclosed.

As far as the claim is concerned that eventually, evidence on efficacy of the drugs tested in the pilot sites enabled government to shift its position, the same interviewee argued that, "there has been evidence since 1996 … For example, a consultation on the use of ARV treatment was held in November 2001 with people from government, academia, medical academics, etc and the Bredell Consensus Statement on the Imperative to Expand Access to ARV Treatment[18] was issued." The Statement underscored the need for implementation of ARV therapy as a matter of urgency to HIV prevention and treatment and therefore should no longer be withheld as a result of government policy. So, there was no justification for the lengthy delay. There was ample ground to begin providing people with treatment at a much earlier stage and the consequence with the delay was that government ended up with larger

[18] **A**n expert consultation, that was hosted by the Treatment Action Campaign (TAC) on October 18th and 19th 2001, of doctors, scientists, nurses, policy specialists and activists to discuss the benefits of using ARV therapies for the treatment of HIV and AIDS in South Africa (http://www.essentialdrugs.org, 2004).

numbers of women suffering from AIDS and newborn babies needing treatment.

Another factor that contributed to a change in position, according to an explanation from the official from the Gauteng Provincial Department of Health, is that it was possible as a result of government's successful interventions in the drug-pricing arena:

> Government forced the pharmaceutical companies to reduce the price of the drugs. I do not know anyone else in the world that has managed to do that and bring a case against the companies that were as a result forced to reduce the price of the drugs. The government has gone a step further to register some of the generic drugs that could be made locally to make them even more affordable within the legal constraints. And it accepted donations from some of the pharmaceutical companies, donor funding from outside and technical support that made it possible for that matter.

The respondent from the TAC, however, dismissed the claim that it was government which eventually facilitated a reduction in medicine prices, by asserting that "legally, the government could have used its powers to issue compulsory licenses that would have dramatically reduced the price of the medicines. It did not have to wait for the drop in drug prices to happen".

Contrary to the opinion expressed above by the official from the Department of Health, the TAC activist contended that one reason for government's change of position was the strong public pressure that was leveled against the government in a range of different ways. This pressure came from, *inter alia*, medical professionals, from the TAC and other organizations, even from within the ANC and from the international community. In the international arena, the shift in consensus that led the WHO to make a commitment to treating three million AIDS patients worldwide by the end of 2005. Another example is, as has been noted above, the Doha Agreement which explicitly recognized the impact of

patents on the price of medicines and makes explicit reference the remedies that are available to states are some cases that deserve mention.

The respondent from WALP suggested that the shift in position emanated from the realisation by government authorities that the state could no longer continue with its initial policy as it contravened national and international opinion and legal obligations. Therefore the change in position was certainly a development starting from government's April the 17th 2002 commitment to a comprehensive programme on the implementation of treatment policy on HIV/AIDS. This had served to reiterate government's commitment to the *HIV/AIDS and STI Strategic Plan for South Africa, 2000-2005*. It was followed by Cabinet's approval of the *Operational Plan for Comprehensive Treatment and Care for HIV and AIDS* in November 19, 2003, which it had, on 8 August 2003 requested the Department of Health to prepare. Amongst other things, the Plan provides for anti-retroviral treatment in the public health sector, as part of a comprehensive strategy to combat HIV and AIDS.

All the above developments led the National Department of Health to a point where it was not sustainable to continue with its denialist position. This arose partly due to an "opposition threat at the highest levels of the government", the interviewee commented.

In trying to explain government's ultimate change in position, the respondent from Chris Hani Baragwanath Hospital provided an additional explanation by suggesting that,

> Basically government did the numbers game because it made economic sense; it was thus not a moral/ethical imperative... So government did the calculations in a sense if it provides ARVs it could defer deaths so people are kept economically active,… the number of orphans is reduced, the cost of hospitalization, opportunistic infection treatment, the burden of HIV on the public health sector and social service sector etc will also be reduced to a large extent.

Thus, the interviewee stressed that government authorities, *inter alia*, Cabinet ministers and senior officials in the Department of Health saw the detrimental socio-economic impact of the epidemic and were eventually convinced that there needed to be a response that largely includes providing access to ARV treatment.

However, the TAC activist warned, "it is a mistake to think that the South African government has a homogenous position on this issue. I do not think at the top of the leadership of the government there is any change; it is a reluctant shift." He argued that if government had genuinely changed its position, "it would have done it as far back as April 2002 when the Cabinet recognized that the drugs work, but it took another two years doing nothing about it." In substantiating this claim, the respondent accused the Minister of Health of failing to follow the Cabinet's commitment of November 2003 (a National Treatment Plan for HIV/AIDS) which recognized, for example, the need for ARV medicines for half a million people by mid - 2003. Thus, the interviewee concluded - in line with other findings made so far in the context of this dissertation - by attributing the main cause of the delay to the government's political obstruction.

From the discussion of the presented data against the reviewed literature, it appears then that among the various factors that have led the government to finally commit to a radical shift in position with regard to national ARV rollout programme to HIV positive pregnant women were the result of a combination of strong local activism and opposition from NGOs; opposition from within the government itself; a changing international environment, as exemplified by the shifts in consensus of some international organizations such as the WHO and the WTO; a considerable reduction in the price of the drugs, and lastly, the huge and detrimental impact of the epidemic on social capital and on the economy of the country as a whole. Nevertheless, it would be naïve to conclude

that there has been a fundamental change of position in government as a whole.

The summary and conclusion chapter will bring together the arguments brought in the preceding chapters and will provide conclusions on the basis of the findings and analysis of data.

CHAPTER EIGHT
SUMMARY, CONCLUSION AND RECOMMENDATIONS

This chapter will provide a summary of the entire study. It reviews the issues discussed and draws conclusions based on findings and analyses of data in the preceding chapters of the research. Finally, recommendations will be made with a view to help the smooth implementation of ARV rollout programme.

In the first chapter, general information was presented on the historic development of HIV/AIDS from the early 1980s, the different modes of transmission (that is unprotected sex, contact with infected blood, and through MTCT). Different aspects of treatment and prevention were also discussed. The present scale of the epidemic globally and in South Africa (about 37.8 million and around 7 million respectively) was emphasized, as well as the various socio-economic, cultural and political factors that have contributed to the existing high prevalence of the epidemic in South Africa. It was found that such factors include poverty and socio-economic inequality, the migrant labour system (both within South Africa and from neighboring countries), unequal gender relations, and the nature of policy responses which have been characterized by confusion, denial, and unreasonable delays in the implementation of available treatment and prevention options. To this date, there is no total cure for the epidemic. However, it was found that ARVs can prevent the transmission of HIV from a pregnant mother to her newborn baby/babies. ARVs can also effectively reduce the viral load in HIV infected people.

This was followed by discussion of the conceptual development of human rights from the 18th Century onwards. The discussion underscored the universal, indivisible, interrelated and mutually reinforcing nature of different generations of human rights, that is, civil, political, socio-economic and group rights. It was found, however, that

the current global dominance of neoliberalism - as an ideology and a set of economic policies - has negatively impacted on the prospects of realizing socio-economic rights, especially in Third World countries. It was pointed out that the South African government, too, has embraced neoliberalism as a guiding framework for policy making, as demonstrated in its adoption of the Growth, Employment and Redistribution strategy.

Thereafter, basic concepts of human rights and their relevance for the protection and promotion of health rights were outlined. The impact of a lack of human, especially health rights on the spread of the AIDS epidemic was explored viz-à-viz a selection of international human rights bodies and covenants. South Africa has signed and ratified many of these agreements, which constitute binding obligations for signatory states. In view of the hindering role of South Africa's neoliberal policy framework in relation to the realization of health and other socio-economic rights, contradictions in the process of social, and health, policy implementation seem like an inevitable result. In this context, the importance of vibrant civil society organizations was debated. It was highlighted that it is crucial for members of civil society to know the relevant human rights statutes and bodies so as to be able to protect and promote people's health rights.

This was followed by a discussion of the complementary and mutual reinforcing relationship between human rights, public health and the values, knowledge and skills base of the Social Work profession in advancing and protecting people's wellbeing. In the context of the AIDS epidemic, for example, stigma was found to be reduced as the protection of the human rights of people infected and affected by AIDS was improved. To this end, it was found that the profession of Social Work is in a position to play a crucial role in enabling structurally disadvantaged groups, such as HIV positive pregnant women, to regain an improved standard of living. This is so because, according to the IFSW's definition

of Social Work, the profession's theory, practice, and value base are inseparable from conceptions of human rights and social justice.

Several approaches have been identified, which - while they are not necessarily part of the Social Work mainstream - speak well to strategies used by other segments of civil society. These approaches include, *inter alia*, conscientisation, empowerment, advocacy and social action, and appear to be apt conceptual and practice tools for the promotion of human rights and social justice objectives. It has been found that the concept of power is crucial in propelling forward the progressive realization of socio-economic rights in that any strategy to this end needs to consider the power relations that have informed particular policy choices. Social activists - and social workers - need to have a clear concept of how and to what end these power relations are to be influenced.

The next chapter explored the debate around a countrywide ARV rollout programme for HIV positive pregnant women giving birth in the public health sector, a debate that has been ongoing since 1999, and which has involved various stakeholders within and outside government. Arguments against such a rollout concerned the drugs' side effects, huge cost, alleged lack of adequate scientific evidence on the effectiveness of the drug, claims of a lack of evidence supporting the relationship between HIV and AIDS, and lastly, insufficient infrastructural capacity of the South African health care system. It was found, however, that none of these arguments were fully sustainable when contested argumentatively, thus suggesting that at their root may well be a lack of political will. While some possible explanations have been proposed, it has not been possible to explore in detail the root causes of this apparent lack of political will.

However, the discussion did raise the question of power and ideological contestations. In the course of the argument, the cost factor (that is the alleged unaffordability of antiretroviral drugs in view of the global patent

laws; and the subsequent assertion that a realization of the right to access to ARV treatment on giving birth was affordable only at the expense of other socio-economic rights) has held a central position. While such arguments appear to make some sense from a neoliberal perspective, it was found nonetheless that in terms of GDP, ARVs appear to be not only affordable but also cost saving. It follows that such arguments invert theoretical assertions and claims from within civil society that different human rights and public health policy do enjoy a complementary, rather than a contradictory, relationship. It was therefore found that the South African government's lack of consistency and delay in implementing the said ARV rollout programme has happened in tandem with a use of political power to distort central notions of human rights. In challenging such an abuse of power, civil society organizations have employed strategies of conscientisation, social action and advocacy alongside legal action around the human rights of HIV positive pregnant mothers. This has ultimately led to the South African national government agreeing to rollout the drugs, even though implementation has subsequently been delayed, again. Although part of the reason for the least access to ARVs was found in the pharmaceutical manufacturers which attempted to prevent the government from making less expensive drugs relying in part on their property rights, part of the problem was solved in the agreement that was reached in Doha in 2002 that authorized governments to take reasonable measures in times of emergency to achieve effective health services to their people.

In the chapter which followed, qualitative data gathered from a purposive sample representing a cross spectrum of views within and outside the South African government was presented and analyzed. The findings show that in the last five years, a number of barriers have prevented the government from implementing a comprehensive national ARV rollout programme. Barriers that were mentioned by the research participants reflected and refined all the arguments presented in the literature review, and included the weak capacity of the health care system; questions around the affordability of the drugs concerned; an apparent abuse of

patent laws by some pharmaceutical companies; as well as, in the assessment of representatives from the NGO sector, a lack of political will within certain quarters in government, and finally, allegations of mismanagement of government AIDS budget. While again not being able to fully explain the underlying reasons for government resistance against the use of ARVs, the barriers referred to by respondents from the government sector were considered by respondents from the NGO sector as delaying tactics employed by the government to delay having to fulfill its constitutional duties.

In forcing the South African government to implement the Constitutional Court's order to start a countrywide ARV rollout programme for HIV positive pregnant women giving birth in public health facilities (see p.70), the Court has been constrained by its limited power. It can only play a supervisory/monitoring role, a role which is in turn constrained by the interpretive nature of the relevant sections of the South African Bill of Rights, which require government merely to realize the right to access to health care progressively and within available resources. Resultant delays in the implementation of the order have had further negative impacts on poverty and inequality.

In view of the limited role of the legal system, respondents from the NGO sector confirmed the findings of the literature review regarding the potential of strategies such as conscientisation, advocacy and social action to shift existing power relations in favour of otherwise marginalized members of society. In other words, such strategies can indeed help to redistribute power from political and capital elites as represented by the South African government and international pharmaceutical companies, respectively, to HIV positive pregnant women. The prominent role of human rights in this context - both as a public discourse and a legal system - has been highlighted by all respondents.

In view of the above findings, it may be concluded that despite the national government's claim to have adopted a plan for meeting the AIDS crisis, in practice, it has done very little to address the issue, and efforts to combat the disease appear to have been generally accorded a low priority. As a consequence, it appears that many people have unnecessarily been exposed to the suffering of the disease, especially, and that has been the focus of this study, pregnant women and their newborn babies, the latter which could have been prevented from contracting HIV in the first place.

Although the South African government has claimed that it is taking all the necessary steps towards realizing the human right of individuals to health, however, it has been misleading the public with scientifically refuted messages such as discourses about the dangers of the best available drugs for stopping the progression of the virus and preventing MTCT. Despite court orders to make ARVs available to HIV positive women giving birth at public health centers countrywide, and despite government pledges to introduce a programme that offers*, inter alia,* to expand MTCTPs nationally by the end of 2002, meaningful implementation of this programme is still not a reality and its prospects remain dependent on the continued pressure from civil society.

Although human rights have been employed as powerful tools for the realization of unfulfilled human rights by structurally disadvantaged members of society, in the case of AIDS, the politicization of the issue by key personalities within government has undermined the ability of the state to direct its united effort towards fighting the epidemic. It is under such circumstances that the question of human rights has become subject to what has been found to be unreasonable contestation. Many members of government both at provincial and national levels have used the political power vested in them to shape the discourse in a way that escaped the main argument. Alleged contradictions between the notions of different human rights, public health and development objectives have been asserted, thus justifying claims that choices needed to be made

between alternatives while it may well be argued that such choices needed not really be made.

Yet, public health programmes can be enhanced to respect and address human rights. Such programmes encourage people to trust and cooperate with public health authorities. The promotion of human rights will also help to enhance people's access to health. Indeed, because of the complementary nature of human rights, government efforts to promote people's right to health are bound to impact on a broad range of other human rights such as the right to life, the right to dignity, and freedom and security of the person. In the case of the AIDS crisis, it is however important to note that human rights are not a cure to the AIDS crisis. In order to successfully fight the epidemic, Roth (2000), notes the significance of government addressing the crisis with the appropriate urgency and transparency. He warns that, "human rights alone will not magically produce the resources we need. They will not even tell us which resources should be devoted to fighting AIDS as opposed to addressing other important societal needs and interests" (ibid, 4).

The South African government's current lack of commitment to implement policies that would make the provision of ARVs possible at state hospitals and clinics is not only a matter of saying 'yes' or 'no' to these drugs. It raises the concept of government's role in the policy making process. Government, as elected by the people, and as the main representative of the people in the state and its political organs, should work in the interest of the majority of South Africans who are unable to afford expensive medical treatment. It should also settle matters of such magnitude through democratic negotiations even if this means having to radically change positions previously held as a result - since it is only the South African government that has been opposed to the treatment of HIV with ARVs against all the political parties, the trade unions, court rulings, and the views expressed by national and international NGOs.

At this crucial moment the South Africn government needs to implement the values contained in the Constitution. For example, the right to life, which is enshrined in Section 9 of the Constitution, is a right not simply to biological existence but to a dignified life. If this fundamental right is violated, the very core of the country's democracy is threatened (Langa cited in Posel, 2004:8). As Judge Pius Langa puts it, "……the state is a role model for our society. A culture of respect for human life and dignity, based on the values reflected in the Constitution has to be engendered and the state must take the lead" (ibid). Thus, in one way or another, treating HIV patients with ARVs means asserting constitutional rights to life and dignity, respecting socio-economic rights that keep other rights in balance, and improving the trust of the people in the government.

For this reason, the government needs to start rolling out the drugs - especially to those who lack access to adequate nutrition, sanitation, potable water and so on - before their situation further deteriorates. The argument at this point is that unlike other poor countries, South Africa can afford both nutritional and treatment programmes. So, there is no sound base for the government to prioritize one programme (socio-economic right) at the expense of the other.

However, given the South African government's stance as documented in this study, it is reasonable to assume that implementation of the rollout programme may be further delayed. The impact of the epidemic is therefore likely to grow to a plateau stage in the coming few years. The cumulative effects of the high infection rates, subsequent increases in poverty levels and rates of inequality threaten to form a vicious cycle where the epidemic will drive more people into deepening poverty, while at the same time, poverty will further accelerate the spread of the epidemic. Under such circumstances, in the absence of sufficient professional help, universally accessible treatment / means of prevention, and in the absence of adequate institutional resources, the epidemic will have a huge and catastrophic impact in terms of the loss of human life and on the national economy. In redressing such degrees of

social injustice and in seeking to tackle health-related inequalities, the role of Social Work is significant.

If Social Work's commitment to human rights and social justice is to be fully attained, inequality must be placed as a top agenda in the setting of practice goals and intervention purposes. Indeed, social workers are in a unique position to advance the interests of marginalized members of society by serving as service brokers; by representing clients' interests; and by lobbying for access to treatment.

Characteristic elements of the type of practice that might help realize access to treatment are: direct contributions to increasing the material, environmental, personal and social resources required by HIV positive pregnant mothers and their newborn babies; collaboration in building up the infrastructure of interest groups, locality-based activism or self-help organizations in the interests of redressing discrimination; and advocacy or brokerage with other concerned professionals to ensure greater equity in accessing available professional care and treatment and greater equality in the care received (McLeod and Bywaters, 2000:9). To this can be added the profession's role of providing effective leadership in the fields of policy, practice, research and endeavors in community development.

Such practice would require social workers to give greater meaning to concepts such as conscientisation and empowerment in their daily work and to attribute greater importance to approaches such as social action than may have been the case in the past. The implications of the findings of this study for Social Work methodology is that the issue is complex; it requires sophisticated conceptual, technical, tactical as well as political skills and knowledge; a clear vision; as well as a willingness to engage in prolonged conflict when dealing with the epidemic.

However, the benefits of making such a shift would be that social workers could demonstrate the profession's relevance to people

suffering from structural forms of oppression, such as those who are infected and affected by HIV and AIDS while at the same time depending on the public health care system. For example, by advocating people's right to equitable and accessible health care services, social workers would engage in the fight against poverty and inequality as well. They can put pressure on national government to fully adhere to the principles of human rights that are enshrined in the country's Constitution and other relevant regional and international conventions it is signatory to. In so doing, it is crucial for social workers to work closely with those affected by the epidemic, their representative organizations, and decision makers.

For such Social Work interventions to be effective, there has to be room for interdisciplinary dialogue and collaboration. Outside the legal field, the task is manifested in the close link that exists between the discipline itself and, for example, health education. In order to make health education and HIV/AIDS prevention programmes successful, social workers can well offer their professional abilities in the community context within which they serve; skills in communication, consultation and policy making; knowledge of human behaviour and community organization; methods and approaches which aim at bringing about change in the balance of power and resources; and last but not least, knowledge in the area of research.

In addition, knowledge and acquisition of legal strategies is crucial for social workers. This is because, according to Cull and Roche (2001), effective and ethical practice relies upon a commitment to develop and consolidate legal knowledge. The law is an indispensable partner for Social Work. It, among other things, regulates the profession's practice; provides social workers with specific legal powers and duties in a range of situations so as to do their job properly, with making sound decision making, and with the authority they need as professionals. In the context of this study, it can be noted that the attainment of people's access to equal health care relies considerably on the development and

manipulation of legal knowledge. Social workers will be in a better position of serving their HIV positive clients and others affected by the epidemic if they are familiar with appropriate legal principles / legislations that foster human rights-based social and health policy and practice. It is thus essential for social workers to be familiar with the relevant national and international laws and agreements.

As for discourse and power, government has shown to have the power and the will to use such power to redefine the nature of human rights discourses so as to divert attention away from its neo-liberal spending priorities. It is therefore important for Social Work as a profession to participate in public debates and to demonstrate its commitment to human rights and social justice.

On the basis of the findings of the study, it is possible to make some recommendations and measures that the different stakeholders involved in the issue might adopt in the matter of providing access to antiretroviral treatment for all HIV positive pregnant women giving birth in public health care facilities.

a) The South African government has to show a much higher degree of political commitment to providing such access - without further delays - than it has done so far;

b) Government should adhere to the values that are enshrined in the country's Constitution and the various court rulings, as this would imply consolidating democracy and enhancing people's trust in government through advancing their wellbeing;

c) In so doing, government should transparently work together with those organs of civil society who opposed its previously held position with regard to comprehensive ARV provision to HIV positive pregnant women and their newborn babies; and

d) Government should simultaneously implement the rollout programme while strengthening its infrastructural capacity, as is the case in some developing countries (eg. Brazil and Botswana);

e) In order to facilitate the implementation of the above points, social workers - as agents of social justice, human rights and equality - should work closely with government in providing information, assessing / monitoring government's compliance, and strengthening existing infrastructural capacity for a speedy implementation programme so that the aspirations of the country's democracy are realized;

f) Social workers should especially strive to make pregnant women aware of possible HIV infection during pregnancy and the importance of testing and existing Prevention of Mother to Child Transmission Programmes. They should help to develop public awareness of the nature of ARVs, and importance of nutrition when taking ARVs;

g) Social workers should also work with communities and other organs of civil society with a view to enhancing their knowledge / awareness of people's constitutional rights, organizing around such constitutional rights and articulating their claims to the realization of these rights effectively.

h) There seems to exist limited knowledge of in how far practicing social workers in the field of HIV/AIDS in South Africa engage human rights discourses and apply conscientisation / empowerment / advocacy / social action approaches; or the degree to which links between human rights discourses, power and ideology, or the impact of neoliberalism on the realization of human rights and social justice, are understood. These are some of the crucial issues that need further consideration;

i) If these issues are indeed important perspectives on Social Work practice - an assertion made in this study - then it becomes important to further investigate the degree to which they actually inform current

Social Work practice in South Africa - its theoretical and methodological development, and its values debate.