THE UNIVERSITY OF CAPE TOWN

GRADUATE SCHOOL OF HUMANITIES

Assessing Responses and Interventions to Orphans and Vulnerable Children Affected by HIV/AIDS: A Case Study of the Experiences of HIV/AIDS Orphans and Vulnerable Children in Gugulethu, Cape Town

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by

Mr. Mesele M. Seyuba

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Abstract

This study examines how children who are exposed to the impact of HIV/AIDS in their immediate families are affected; what their experiences are and what coping strategies they employ on a day to day basis. Such children are referred to as HIV/AIDS orphans and vulnerable children (OVC). Furthermore, the study examines the response proposals of key role players, such as government departments, civil society organisations and the affected communities, in dealing with the challenges faced by HIV/AIDS OVCs. The examination of these responses enabled one to assess whether the specific experiences of the HIV/AIDS orphans and vulnerable children are considered and addressed by the responses and actions of the key role players The focus here was on the experiences of the OVCs (as told by the OVCs themselves) and how these accounts can be used to shape appropriate responses to their plight. The point of departure from the available literature on the subject is the emphasis on prioritising the subjective OVC experiences as the starting point for any and all meaningful responses

The research was conducted during the course of an internship at a Non Governmental Organisation located in the residential area of Gugulethu, Cape Town, South Africa. The research participants in the study are children and youth between the ages of 13 years and 20 years. All the research participants were drawn from Africa Unite which is an organisation that runs various social and community development projects in many disadvantaged communities in Cape Town. The participants were specifically selected from "The OVC Project" at Africa Unite. Focus group interviews were conducted; interviews were audio tape recorded and then transcribed and analysed using thematic content analysis.

The study found that HIV/AIDS orphans and vulnerable children experience socioeconomic difficulties, psychosocial deprivations and insecurity as a result of parental death or illness. Furthermore, the participants in the focus groups cite the failure of government departments and NGOs, their communities and all other interested parties in addressing their plight. They called for more to be done to mitigate their day to day struggles. Key among these was a call for stakeholders to ensure a sustained conducive environment for their wellbeing, growth and

development. Further findings of this paper show the primary importance of the centre (Africa Unite, through which the case study was conducted) for enabling the children to survive and cope with their daily difficulties. The paper notes that state and private sector efforts have identified the socioeconomic needs of these children as being of primary importance – these include food, shelter and access to education among others. This study argues that the response to HIV/AIDS OVCs must be holistic in its approach rather than focus on the above mentioned areas of needs alone. The study further finds that the participation of HIV/AIDS OVC's in developing responses to their plight is necessary for effective policy formulation and implementation. It argues for the development of responsive policies to the articulated experiences of HIV/AIDS OVCs.

This thesis concludes with policy recommendations for strategic interventions and emphasises participation by the HIV/AIDS OVC's in the policy process, from formulation, implementation and right the way through to monitoring & evaluation.

Acronyms

HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
OVC	Orphaned and Vulnerable Children
UN	United Nations
UNCRC	United Nations Convention on the Rights of Children
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	The United Nations Children's Fund.

Table of Contents

6. Chapter Six – Discussion on "Gaps" in the Responses to HIV/AIDS Orphans and Vulnerable Children

7. Chapter Seven – Recommendations and Conclusions

9. Appendices

1. Chapter One - Introduction

1.1 Overview

The primary aim of this research was to examine and explore how OVCs in South Africa are impacted by HIV/AIDS. The research attempted to gain insight into firsthand accounts of the experiences of these HIV/AIDS OVCs. This was done with the view that such information would better inform policy formulation and decision making to include the views of the actual people these policies aim to assist. Of the information gathered, the responses by the OVCs appeared to focus mainly on emotional well being, social adjustment and the general coping strategies that these specific children employ. It is worth noting that the above mentioned outcomes are outside the traditional focus areas of the responses by the concerned shareholders (i.e. government departments, civil society and the affected communities themselves).

The reason for the prioritisation of this study is the alarming rate at which HIV/AIDS continues to spread and negatively impact on the entire population of Sub-Saharan Africa. Statistics obtained from the Joint United Nations programme on HIV/AIDS (UNAIDS) indicate the prevalence rate in the region at 7.4% with an estimated 25 million people currently living with HIV/AIDS. It is further reported that the region while having only 10% of the world's population has about 60% overall, of people (including children) living with HIV (UNAIDS, 2006: 2). In sub-Saharan Africa, about twelve million children have lost at least one parent to HIV/AIDS; all these children are under the age of 17 years, with an overall number of 48 million being orphaned (UNICEF & UNAIDS, 2006: 2). It is therefore widely acknowledged that due to the spread of HIV/AIDS children are becoming more vulnerable and will face greater risks.

Sub-Saharan Africa carries 63% of global HIV infections as well as the world's highest unequal distribution of wealth (UNICEF & UNAIDS, 2006: 2). The same is true of the epidemic in South Africa where HIV prevalence is high and it is also concentrated in the poorest areas and among the most vulnerable populations. Steinberg & Cutter (2008) conducted a survey of HIV affected households in South Africa. It was established that 44% of these households had an income of less than R1000 per month and only 43% of these had

piped water in their dwelling. Furthermore, 68% of caregivers were women and girls (Steinberg & Cutter, 2008: ii). HIV prevalence in South Africa in 2008 was estimated at 11% of the general population. This translated to approximately 5.3 million people (Stats SA. Mid Year Population Estimates 2008: 3, 6). Coupled with this, statistics state that of all the children in South Africa, 43% have inadequate access to water, 49% have inadequate sanitation and 12% live in informal settlements (Jacobs, 2004: 6 -62, 64). Children of lower class families also complete fewer years of school than children of middle or upper class families – it has been argued that the consequence of this is that poor families fall into a vicious cycle of poverty (Seekings & Nattrass, 2005: 265). Added to this, living conditions are characterised by overcrowding within the household and densification in the community

The field work for this study was conducted with a non governmental organisation called Africa Unite (AU). This organisation carries out a number of community based projects in Gugulethu on the Cape Flats. The various projects at AU are focused on empowering HIV/AIDS OVCs among other groups. They include maths and science literacy programmes, drama club and social sports among others. The researcher worked with this organisation as an intern in the second half of 2007 beginning in the month of May and a further two months during the course of 2008 (July to September). The internship involved gathering information about "The OVC Project" to be used to develop a proposal to seek further funding for the continuation of the project for the second year of its 3 year cycle.. Furthermore, the researcher was conducting interviews and gathering material that would be used to inform the pilot study for this dissertation.

A deeper appreciation and interpretation of the research problem at hand and the findings of this case study is achieved by a conceptualisation and outlining operational use of the key reoccurring concepts referred to in this report. The first of these is 'HIV/AIDS Orphan', defined by UNAIDS as a child under 18 years of age who has lost their mother (maternal orphan) or both parents (double orphan) to AIDS (Skinner et al., 2006: 620). Then we have 'Vulnerable Child', also defined by Skinner (2006: 623-4), as someone who has little or no access to basic needs or rights . . . this is in the context of material problems, emotional problems and social problems. Historically, the first group to gain attention was "orphans due to AIDS": children who had lost one or both parents to AIDS. However, those children who

were living in households with HIV were also facing unusually difficult challenges, so vulnerable children were added – "orphans and vulnerable children due to HIV/AIDS." Yet, the stigma associated with HIV/AIDS led many to remove the reference to AIDS – "orphans and vulnerable children." This last classification served as a proxy for children affected by HIV/AIDS. For the purposes of this study, an HIV/AIDS OVC includes an HIV positive child, children directly affected because one or both of their parents have died from HIV/AIDS and children who are directly/indirectly affected because one of their parents or caregivers is infected with HIV.

As cited in the Children's Act (2005) of the Republic of South Africa a child is defined as a person under the age of 18 years (Act No. 38 of 2005). The rights of a child in the context of this study are elaborated on in the constitution that states, among other things that a child has a right to:

Family care or parental care, or to appropriate alternative care when removed from the family environment;
Basic nutrition, shelter, basic health care services and social services;
Be protected from maltreatment, neglect, abuse or degradation;

A child's best interests are of paramount importance in every matter concerning the child (section 28 of the constitution).

While the constitution defines a child as a person under the age of 18 years, this research included OVC participants up to the age of 20 years. This is an obvious variable in determining the results and findings of the research and it is believed that rather than limit or weaken the validity of conclusions drawn, including youth up to 20 years serves to strengthen the findings in this paper and the subsequent arguments put forward.

In order to better understand the experiences of the children (i.e. the OVC Project beneficiaries), the researcher began by conducting a review of the literature related to the experiences of other HIV/AIDS OVCs in Sub Saharan Africa. This includes the limitations on the extent and focus of the review. Following this, the researcher reviewed the policies available in South Africa that address issues affecting OVCs, the current lobbying and efforts

being made by civil society organisations in this particular subject area. This is explored in detail in Chapter 2. Chapter 3 discusses the main tenets of public policy formulation. This is the theoretical framework on which the main argument of this thesis is based. The aim of this chapter is to outline theoretical guidelines that can be used to establish whether or not the responses to the problem of HIV/AIDS OVCs are appropriate and effective. The methodology of this empirically based research is discussed in chapter 4. It is here that an overview of the case study is given. The case study provides us with a local lens through which to assess the effectiveness of existing policies, and make recommendations that will result from documenting the lived experiences of the study participants. This chapter includes a discussion of the limitations of the study (in terms of the specific focus area and the exclusion of otherwise important subject areas not necessary for the purposes of this thesis. This follows on from the limitations discussed in the literature review). It also contains the research methods used to obtain information for the study and how the results were analysed and used to inform this thesis. Chapter 5 details the findings of the study conducted and separates these findings into main and reoccurring themes. This chapter focuses on the lived experiences of the OVCs. It also explores the dynamics within the OVCs lives, and how effective their own responses to these experiences have been. Chapter 6 delves into the gaps in the responses to HIV/AIDS OVCs. This chapter is separated into three key response areas to allow an in-depth and critical analysis. The thesis ends at chapter 7 where recommendations and conclusions are made. The focus for these recommendations is to increase the effectiveness of interventions by promoting the participation of the OVCs in the processes of formulating policies that aim to assist them as beneficiaries, and to minimise the various multifaceted vulnerabilities that they experience.

This thesis argues that current efforts in responding to HIV/AIDS OVCs are neither sufficient nor effective if judged by the OVCs in the case study. The arguments follow the logic that shareholders and other concerned parties need to take into account the views and opinions of the OVCs in order that their responses can be better suited to the articulated concerns of this group in society. This logic emerges from policy and programme development theory that advocates a 'bottom-up' approach in which the views and opinions of project beneficiaries are used to inform the policy and programme decisions. This is in stark contrast to the 'top-down' approach in which the policy and programme decisions are made at 'the top' (national

and provincial government level) with little or no understanding of the intricate issues affecting 'the bottom' target group (community and family level).

1.2 Motivation for this undertaking

In a country like South Africa where the social welfare system is inadequate and unable to sustain social safety nets for the population, an investigation into the effectiveness of social welfare policies and their implementation becomes very necessary (Seekings & Nattrass, 2005: 263-4). Such efforts are aimed at exposing "gaps" in existing policy responses to social issues with a view to gather information that can be used to better inform policy development/decision making and thus fill the "gaps". This could not be more true as shown by statistics obtained from a joint UNAIDS/UNICEF (2006: 2) report on Africa's Orphans and Vulnerable Generations indicate that with high HIV /AIDS infection rates amongst adults and only a small percentage of these receiving anti-retroviral treatments, "AIDS will continue to kill parents [and in so doing] . . . increase orphan prevalence for years to come."

Past studies in South Africa on the HIV/AIDS issue have focused mainly on determining the social and economic effects of the pandemic on the population as a whole. Little to no attention has been given to the HIV/AIDS OVCs as a uniquely affected group within the general population that needs specific and directed attention. A more directed focus on HIV/AIDS OVCs would allow for this affected group to articulate their life experiences in order for these experiences to be taken into account towards informed responses to their plight. This study will make a contribution to the understanding of the social, emotional and other vulnerabilities that youth and children experience in relation to their status as HIV/AIDS OVCs. It is hoped that the South African government amends its policies and programmes as a result of this and other research undertaken that confirms this hypothesis and the researchers field experience. It is with this in mind that the aims and objectives were formulated to guide the research.

1.3 Research Aims and Objectives

The following questions underpin the primary aims and objectives of this research.

1. How are 13 to 20 year old OVCs in Gugulethu, Cape Town affected by illness or death caused by HIV/AIDS in their immediate, nuclear families?

2. What are the day to day life experiences of these HIV/AIDS OVCs?

3. Are the responses of the communities, other civil society actors and government to these experiences appropriate and/or effective?

4. In what way, if any, do the research findings suggest ways in which current government policies be made more appropriate and effective?

These questions stem from the hypothesis that the absorption of HIV/AIDS OVCs into their extended family is not always conducive to the best development and wellbeing of these children. It in fact proves to be detrimental to both the OVCs and their extended family members. As convenient as this arrangement may seem, several other systemic and symptomatic issues have to be taken into consideration and remedied before it can be expected that the extended family is the best option for foster care for HIV/AIDS OVCs. In a nutshell, extended/foster families need to be supported a great deal when they take on the responsibility of caring for and ensuring the wellbeing of the HIV/AIDS OVCs they take on. This hypothesis was developed after preliminary contact and conversations with the project beneficiaries at Africa Unite's OVC Project. In these conversations, the HIV/AIDS OVCs mentioned directly or insinuated that they would rather explore other alternatives for their care than absorption into their extended families. This became the basis of the research

The objective of this research became to find out why the HIV/AIDS OVCs in this case study felt this way (i.e. what are their subjective life experiences), then to champion a shift in policy thinking to include appropriate responses to these experiences.

2. Chapter Two - Literature Review / Nature of the Problem

2.1 Introduction

The focus of the literature review is three fold. Firstly to demonstrate the extent of the problem of HIV/AIDS OVCs, secondly to touch on what responses have already been undertaken to assist them and thirdly to review the articulated experiences from a social psychology point of view. These are the three main lines of thought that this literature review shall take. For each of these three sub categories there are a set of authors (and studies) that will provide context for the research.

Most of the information regarding the extent of the problem of HIV/AIDS OVCs is taken from sources such as the United Nations through its various sub organisations. In particular, this thesis draws on information from the United Nations Children's Fund (UNICEF) and the United Nations programme on HIV/AIDS A (UNAIDS). Further information detailing the extent of the HIV/AIDS OVC problem is sourced from the following key authors Seekings, Nattrass, Olson, Calhoun , Tedeschi, Foster and Williamson among others.

The policy issues are tackled by way of an analysis of white papers formulated by the relevant government departments. This is also considered in the context of the global/international response to HIV/AIDS related issues and issues affecting children. Here again the main source of information are the global organisations (The United Nations and its various sub organisations) and local South African government department reports. As hypothesised during initial contact with the research participants, there are social psychological issues affecting OVCs that require as much focus and attention as the other aspects that ensure the wellbeing of children. The school of thought led by key authors Broome, Berk, Calhoun and Janoff-Bulman suggest that these social psychological issues are a heavy burden for children to bear without assistance.

HIV/AIDS continues to ravage, mainly, the adult population of Sub-Saharan Africa. Consequently, many children are becoming orphans with little or no prospects of a real future (UNICEF, 2003a: 23). Added to this, HIV prevalence rates in the region continue to be the highest in the world (UNICEF & UNAIDS, 2006: 2). As this number increases so does the

number of orphans that inevitably result. Indications are that "HIV/AIDS has killed one or both parents of 14 million children currently under the age of 15. The numbers continue to escalate. By 2010, the total number of children orphaned by AIDS is expected to reach 25 million". (UNICEF, 2003a: 23). This is an estimated 30 per cent of the 53 million anticipated orphans from all causes currently in sub Saharan Africa (UNICEF & UNAIDS, 2006: iv).

South Africa is reported to have a high HIV prevalence rate of 11% which translates to approximately 5.36 million people (Stats SA Mid-Year Population Estimates 2008: 6). In addition, the country has one of the highest mortality rates (due in part to HIV/AIDS), coupled with projected life expectancy currently at age 52.2 years (Stats SA Mid-Year Population Estimates 2008: 6). As a result of these aggravating factors, the number of orphans in the region also continues to increase dramatically. Over 12 million children in Sub Saharan Africa under the age of 18 years have lost one or both parents to HIV/AIDS . . . [and] out of the children currently under the age of 18 years orphaned by HIV/AIDS worldwide, close to 80% live in Sub Saharan Africa (Olson, 2008: 4). Because of the relatively high HIV prevalence rates in South Africa, it can be argued that many of these HIV/AIDS OVCs live in South Africa.

It therefore goes without saying that long term solutions will need to be established for these OVCs, because the impact of HIV/AIDS will linger for decades after the epidemic begins to wane. Even if rates of new infections were to level off in the next few years (as it is projected will happen from 2012 onwards[1]), the long incubation period of HIV means that mortality rates will not plateau until 2020. Thus, the proportion of HIV/AIDS OVCs will remain unusually high at least through to 2030 (Bradshaw et al. 2002: 2).

For a variety of reasons, little attention has been paid to the particular circumstances of OVCs affected by HIV/AIDS. Olson (2008) argues that when programmes target only AIDS orphans, they create problems by both privileging and stigmatising the children receiving the service (Olson et al., 2008: 4). However, it has become increasingly evident that a greater understanding of the impact of HIV/AIDS on children is important in the design and

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[1] See appendix D, Figure 1 showing waves of the AIDS epidemic from the MRC Policy Brief No 2. May 2002 entitled "Orphans of the HIV/AIDS epidemic"

evaluation of policies and programmes to support such children living in difficult circumstances. This must be considered in light of the fact that HIV is a serious problem particularly in this region (demonstrated by the high prevalence rates mentioned above) and that by responding to the effects on OVCs, stakeholders and other relevant role players eliminate many of the negative impacts on the life experiences of OVCs in general. This would be like the proverbial "killing two birds with one stone" where the responses deal with the effects of HIV/AIDS and also respond to the increasing numbers of OVCs from all causes.

Traditionally, here in South Africa as in many parts of Africa, when parents die, orphaned children are usually absorbed into the families of their immediate relatives as a matter of course (UNICEF & UNAIDS, 2006: 14). However, because of the extent of the HIV/AIDS epidemic (and many other contributing, aggravating circumstances such as poverty), families are no longer able to cope. This is partly because multiple members of one family group may contract AIDS and become incapacitated by the disease and later die, sometimes even around the same time (UNICEF, 2003b: 23). The result of this is a growing number of children who end up living without their parents and having to cope through various means. The situation is worrying as more children are left to fend for themselves. In several instances these OVCs have to take on the responsibility of 'head of the house' and, depending on their circumstances, they may even have to look after and provide for younger siblings (UNICEF & UNAIDS, 2006: 16).

2.2 Literature on Issues Affecting Orphans and Vulnerable Children

As a result of their parents' deaths, children are impacted in several ways including emotional wellbeing, physical security, mental health as well as overall health. (UNICEF, 2003b: 23). Available literature supports this view. There is an overall negative impact that is experienced by these children, that unfortunately, because of high levels of poverty in certain areas of this country (such as the case study area, Gugulethu), only seems to get worse and undermines the best interests of the affected children's development. It is important at this point to consider what is in the best interest of the child. Olson et al (2008:3) argue that children need to be protected from neglect, abuse and the deprivation of their basic needs. Whether in family homes or institutional care, OVCs require extra monitoring and support to ensure their wellbeing. They need loving and constant care, access to health services, good nutrition,

education and interaction with local community life. Interestingly, Olson et al (2008:3) acknowledge that HIV/AIDS "poses a complex puzzle to [the achievement of] this.

Child Mortality

A direct impact of HIV/AIDS infection is usually physical with the OVCs themselves becoming ill, and eventually dying. In many cases, poverty and inadequate resources, and support systems to provide nutrition, shelter and required medication exacerbate the high mortality rate among these OVCs (UNICEF, 2003b: 4). The negative impact of the epidemic on OVCs is not limited to contracting the virus only. Even in instances where children have not contracted HIV from their parent, these children are still at a high risk for illness including malnutrition and other childhood illness (UNICEF, 2003b: 23). This can be attributed to the fact that ill or deceased parents are unable to meet the costs of ensuring good nutrition or healthcare as and when their children need it. Moreover, in a case where a parent(s) is ill, already limited resources may be channelled away from the needs of the children to the healthcare needs of the parents. "As household members fall ill, medical care and other expenses increase while both ability to work and capacity to generate income are likely to decrease. In households affected by AIDS more money [time and effort] is spent caring for sick members, leaving fewer resources for the children in the household. These adjustments can have a particularly harmful effect on children in poorer households, which have fewer resources to begin with" (UNICEF & UNAIDS, 2006: 10).

Psychological Effects

Added to this, the traumatic effects of parental loss can have further negative psychological effects on behaviour, emotions and thoughts (Calhoun & Tedeschi, 1995: 83). Children are equally prone to psychological distress and shock: first at seeing their parent's physical deterioration and helplessness and, eventually with experiencing their death (Gilborn et al, 2001: 26, Ndongko, 1996: 39 - 55). Psychological distress is expressed in varied ways. Depression is a common occurrence; various forms of juvenile crimes are often committed, including the abuse of substances (Gow & Desmond, 2002a: 114). Children may become exposed to alcohol, drugs, and use them as a way of shutting out painful effects (Calhoun & Tedeschi, 1995: 98). Children may continue to carry the effects of trauma long after their parents have died and, even when they have been settled in a new environment (Olson et al, 2008: 14). It does not help that added to this trauma; AIDS still continues to carry a stigma in

many parts of Africa and is still associated with shame, fear and rejection. This is so when the OVCs may not even be infected with HIV themselves and it is yet another negative effect that the children have to endure. (Olson et al., 2008:18).

Economic Survival

Issues of economic survival also have an effect on children orphaned by HIV/AIDS. This is felt primarily through the absence of basic amenities, an inability to enjoy recreational activities and, in many cases, withdrawal from school (UNICEF & UNAIDS, 2006: 2). In a study on adjustment of OVCs, Wild (2001: 3 - 23), further states that children in some cases may end up losing their inheritance. This in itself has serious implications on the material and financial security of the OVCs. An increased incidence of children having to become breadwinners or at least significant contributors to the family finances is not unusual. Children find themselves in a position where they have to forfeit the purchase of books, other academic materials and schooling opportunities, to enter the job market (UNICEF & UNAIDS 2006: 16-17). Because they are unskilled, children end up performing menial tasks that are usually harmful, requiring a lot of effort with minimal wages.

Education and schooling

In some instances, even those children who are able to continue with schooling do not perform well and eventually drop out. Reasons for this have been attributed to lack of parental guidance, poor nutrition and, absenteeism as a result of having to take care of their ill parents [and/or siblings and other dependants] (UNICEF & UNAIDS, 2006: 18 and Olson, 2008: 12).

Health and Nutrition

The economic impact can also be felt with respect to the health requirements of OVCs. As mentioned above, during the continued illness of a child's parents, available resources are normally diverted to obtain what nutritional requirements and medication is needed for the sick parent. More directly, it has also been found that children living with HIV-infected parents are more likely to contract opportunistic illnesses like Tuberculosis, malnutrition and stunting (Basaza & Kaija, 2002: 7 & 10). As a result of their parent's illness, children can no longer obtain adequate levels of childcare and may not even be able attend health facilities because their parents are unable to accompany them. Once the parent dies, even then, that

slim source of funding is no longer available, making access to health care even more unattainable (Gow & Desmond, 2002a: 187).

The OVCs opportunity to receive adequate nutrition is affected; the amount and type of food that children receive is greatly compromised/reduced in a home where one or both parents is HIV positive. Nutritional intake is further reduced when a child is orphaned. A study conducted in Uganda in 2001 showed that orphaned children do not receive adequate food to eat, nor do they have a consistent diet. Older children especially were less likely to eat more than a few times in a week (Basaza & Kaija, 2002: 9).

Poverty

Overall the impact on a household where the main breadwinner is ill or dies due to HIV/AIDS produces a ripple effect. Family income is reduced and that sets off deficiencies in other aspects of the home (FHI, USAID, 2002: 27). The amount of disposable income available to be spent is usually not adequate to meet the requirements of the remaining family members. As a result unavoidable sacrifices are made and far-reaching financial decisions are taken (such as discontinuing payment towards children's schooling, water, electricity and other utilities etc), that ultimately result in the family becoming poorer and more vulnerable (Gow & Desmond, 2002b: 13).

Coping strategies

The increased number of HIV/AIDS OVCs also represents an increased number of children who are working. The number of children between the ages of 5 to 14 years who are working in the Sub Saharan region of Africa is estimated to be at about 29%. (UNICEF & UNAIDS, 2006: 4). At this age, many of these children do not have the physical capacity to perform optimally and invariably this has an effect on their physical development.

Yet another disturbing consequence of HIV/AIDS vulnerability is that families and siblings often get separated after the death of one or both parents. It is still true in South Africa, as it is in many African countries that extended families continue to look after OVCs; but unfortunately it is not always possible to absorb all the children from one nuclear family into an existing family. Hence siblings get 'divided' among the extended family members and

have to be raised in different homes. (UNICEF, 2004: 32). Studies in Uganda indicate that children find this separation particularly stressful as it leaves them feeling further isolated (UNICEF, 2004: 35).

Resilience

Yet, notwithstanding the multiple negative effects that OVCs experience as a consequence of HIV/AIDS, many of them survive. This can be attributed in part to the efforts of government, through policy measures, various non governmental agencies and the communities in which the OVCs live. Additionally, the OVCs have continued to demonstrate resilience in their ability to look after themselves, to source assistance and in general to survive. It may be assumed that to some extent these children, as with most people, possess an inherent degree of resilience.

Social support

The social support that OVCs receive from their peers cannot be ignored in this case. Brannon and Feist (2000: 372) speak about the positive link between good mental and physical health on the one hand and social support on the other. If this is so then to some degree the same should be true for these OVCs as they pass on and share survival skills; much in the same way that family and friends in society, in general, are seen to provide positive input to wellbeing.

Although the literature indicates that the study of the lived experiences among OVCs has received less attention than it is due, it has been acknowledged that children orphaned and made vulnerable by HIV/AIDS need as much support as is available and as soon as possible. It is hoped that directed support will be the best way to respond to the experiences of OVCs and also to work towards measures to alleviate the advent and incidence of HIV/AIDS OVC numbers. It has also been acknowledged that many of the studies done on children affected by HIV/AIDS focused on possible measures to alleviate the hardships associated with their circumstances rather than focus on the responses to HIV/AIDS OVCs with respect to their specific experiences.

The literature review has attempted to look at some of the issues that affect HIV/AIDS OVCs and some of the consequences of their changed circumstances. This was done with the view

to establish whether or not the orphans and vulnerable children in this study experience similar issues around the trauma of changed life circumstances. The literature has also provided information on coping strategies and resilience, and what influences these attributes have amongst different individuals. It is hoped that this work will add to existing literature currently available from South Africa and more so that the information obtained and recommendations made will be used to better inform effective response initiatives.

Further to this, the literature review has demonstrated that though there is a concerted effort towards a response to the plight of HIV/AIDS OVCs, it is by no means sufficient – especially if (as will be seen in the findings chapter) these responses are judged by the OVCs themselves.

2.3 Literature on the Responses to Issues Affecting Orphans and Vulnerable Children

Descriptions of the impact of AIDS on children in Africa first appeared in conference and research papers in the late 1980s. The articles at that time provided estimates of the future scale of the orphan epidemic and described community-based assistance programmes. The World Health Organisation (WHO) and United Nations Children's Fund (UNICEF) were instrumental in disseminating research findings, documenting the problem, analysing responses, and proposing remedies. However, the early writings were not translated into concerted international action with the result that, during much of the 1990s, the problem of children affected by AIDS was given a low priority by United Nations (UN) agencies, development organisations, international NGOs, research bodies, and governments in affected countries. Instead, programmes to support vulnerable children were developed by local groups and organisations, and slowly attention was drawn to the worsening situation of children living in communities affected by AIDS (UNICEF, 2003a: 16). These include publications since 2008 by some members of the Joint Learning Initiative on Children and HIV/AIDS and the various academic studies that have contributed to the SAHARA Journal since 2007.

International Community and Government

The 1997 *Children on the Brink Report* by USAID catalysed a change in responses by the international community to children affected by AIDS. This report documented the scale of

the impending orphan crisis and proposed intervention strategies. During the past decade, international support for responses to the HIV/AIDS crisis has increased significantly, with some of the financial resources being earmarked to assist children and their families. (UNAIDS, 2000: 9)

At the June 2001 United Nations General Assembly Special Session (UNGASS) on HIV/AIDS, governments from around the world drafted and endorsed the Declaration of Commitment on HIV/AIDS: "Global Crisis – Global Action", to fight the epidemic. This Declaration included a set of national strategies and financing plans for combating HIV/AIDS and, with regard to children and HIV/AIDS, the following time bound goals were agreed:

- Reduce HIV prevalence by 25 per cent among young people (aged 15 to 24) in the most affected countries by 2005 and by 25 per cent globally by 2010
- Ensure that by 2005 90 per cent, and by 2010 at least 95 per cent, of young people aged 15 to 24 have access to the knowledge, education, life skills, and services to reduce their vulnerability to HIV infection. (UNAIDS, 2004: 3)

What this report and the subsequent efforts made by the international community failed to account for, and indeed accommodate in their responses to HIV/AIDS OVCs, is the unique and in-depth experiences of the OVCs themselves. International responses to HIV/AIDS OVCs have dealt mainly with efforts to reduce prevalence rates and to increase knowledge and education to reduce the children's vulnerability to HIV infection. What is required in addition to this is recognition that OVCs require access to more services and support from the international community that deal directly with some of the life circumstances that the OVCs find themselves in from the impact of HIV/AIDS.

There is no doubt that the adoption of the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child, has resulted in policies, services, programmes, and adult behaviour being more focused on the best interest of the child. This focus on rights, and their enforcement, stems from a shift in developmental ethos away from the traditional trickle-down approach of external assistance from rich to poor, to an approach focusing on empowerment and participation. Rights-based programmes support rights-holders, who are often the poor, marginalised, and most vulnerable in society, to lay claim to

their rights. A Rights-based approach can rectify many of the distortions that have arisen from a crisis-driven response to children affected by HIV/AIDS, poverty, and conflict, and provide a beacon for moving forward. The underlying principles of universality, indivisibility, responsibility, and participation provide a firm foundation for framing priorities and responses to vulnerable children and families.

Extensive experience and empirical research are being used to direct efforts to support OVCs through the circles of care and influence that surround children, i.e. through families, schools, and neighbourhoods, extending outwards to legislative frameworks and policies that all have a bearing on children's lives. Substantial agreement exists amongst child-rights advocates that what is most needed is a set of collective governmental and community responses to strengthen the commitments of caregivers and households to the well-being of HIV/AIDS OVCs. This should all be supported by constructive national policies and the mobilisation of resources. It is evident that the focus of programmes and strategic thinking must expand from the many small, unlinked initiatives to a coordinated approach aimed at long-term, universal benefits for HIV/AIDS OVCs and all children. Further, a continuum of responses is needed to assist children living in communities affected by HIV/AIDS. At one end of the continuum, specific assistance must be provided for the relatively small number of extremely vulnerable children, including children with severe disabilities, abused children, children without adult support, and children living in and out of the streets; at the other end of the continuum, all children in AIDS-affected communities must have increased access to government- provided social protection in all sectors, including health, education, and welfare provision. Only in this way will the health and well-being of all children, including those made vulnerable by HIV/AIDS, be improved.

The South African government has made some determined efforts towards a response that is better suited to the specific circumstances that prevail in the country. It goes without saying that the circumstances that exist within a nation state may not be the same as those circumstances that exist in other nation states. The assumption that the circumstances in different places are similar is the first short coming of the responses usually prescribed by international community role players.

South Africa has a fairly well-developed system of social security compared to most other developing countries and is on par with systems in some developed countries (Seekings & Nattrass, 2005: 8 - 12). This system includes a non-contributory pension system, as well as a number of social grants aimed at assisting households in caring for children and for the disabled among others. Nonetheless, South Africa's social security system is not without its short comings. Paramount of these shortcomings is the fact that access to these grants is limited. Furthermore, the monetary assistance given by the government through these social grants is not enough to meet the day to day needs of those that they target. Monetary assistance falls far short of the other aspects of assistance required to ensure the wellbeing of OVCs and the families that support them. These families have limited access to these grants and the few that are able to get them receive very little additional assistance and support.

In response to this, government support for home and community-based carers employed by NGOs and community based organisations has increased. The state has also promoted the training of lay counsellors to promote voluntary HIV testing. The national Department of Health estimated in 2004 that there were 40 000 community health workers (CHWs) in South Africa, nearly equal to the number of professional health workers in the public sector (fewer than 44 000) (http://www.doh.gov.za/docs/misc/stratplan-f.html). As impressive as this figure may seem, there are many problems associated with it. These include the poor remuneration and resourcing of CHWs, their 'Cinderella' status in the health sector and the uneven quality of the training they receive. Nevertheless, community and home-based carers have been the backbone of the response to HIV and AIDS. It is interesting to note though that there is no specifically directed effort towards HIV/AIDS OVCs as a priority group within the context of the response to the pandemic. This shall be expanded on later in the paper when discussing the "gaps" in the responses.

NGO's and Other Civil Society Organisations
Because government does not have the capacity to implement their responses to HIV/AIDS OVCs as effectively and as widespread as it would like to, Non Governmental Organisations (NGO) and Community Based Organisations (CBO) are used as the tools with which to do this. Africa Unite is one such organisation and its mandate is set out in its mission statement which reads, "Africa Unite aims to secure and ensure the rights of children through various

projects and workshops that facilitate life skills training and support for an environment that ensures the well being and best development of children"
(http://www.africaunite.yolasite.com). Africa Unite and other such organisations are used conduits through which government implements its objectives in the various sectors. These organisations are guided by policies set out by government to ensure that the objectives of the individual organisations are in line with the overarching objectives of the government and the international community. In so doing, large, in-country NGOs have evolved to provide assistance to children and families, some of them taking on the role of intermediaries for channelling international and national funds to smaller community-based organisations (UNICEF, 2003b: 17). Another example in South Africa is the Nelson Mandela Children's Fund (NMCF).

Affected Communities

Communities most affected by HIV/AIDS OVCs are almost exclusively low income, poor communities. And so it follows that most care for people living with HIV in South Africa is provided at household level, by family members, CBOs and Faith-Based Organisations (FBOs). In the early years of the epidemic, the 'community' was called upon to provide terminal care and support orphaned children with very little resources and support from external sources. Families and neighbours responded, assisting those who had lost breadwinners and absorbing children who had lost parents. However, given prevailing levels of poverty, the impact of AIDS stretched survival strategies to breaking point in many cases.

2.4 Limitations

The limitations on this literature review were deliberate and designed to highlight the main focus of the study rather than appear to be a loose and poorly organised research attempt. This literature review is not meant to be a prescriptive text on all the aspects of the HIV/AIDS pandemic and its effects on OVCs. This is a very important consideration to make to create the distinction between this study and others like it that have been done in the past. The deliberate limitations to the review of the available literature were meant to highlight the core tenet of this paper – the articulated life experiences of the HIV/AIDS OVCs in this case study and the responses of the related stakeholders to this plight. Furthermore the literature review was done in such a way that the extent of the HIV/AIDS pandemic could be

demonstrated so as to highlight the importance of making OVCs a key focus group for directed response remedies.

Another limitation lies in the fact that the data used to compile the report is dated. This is because research was done and written up between. Therefore much of the recent developments around HIV/AIDS OVC policies are not included.

3. Chapter Three – Theoretical Framework: Applying Theory to the case study

What follows is a discussion of the theoretical framework that was used to guide this research. The hypothesis from the onset of this study was that for any response to the plight of HIV/AIDS OVCs to be effective, it must involve the documentation and use of the experiences of the beneficiaries/recipients to inform the formulation, implementation and evaluation of the said responses - that is to say, more emphasis on a bottom up approach as opposed to a top down approach in formulating policy to assist HIV/AIDS OVCs.

This chapter will therefore use the theory of public policy formulation, implementation and evaluation to help make sense of the interrelated concepts and the relationships between the factors in the case study. To this end we shall measure the scale of problems affecting the OVCs in the case study and how effective the stakeholder responses to these problems have been in terms of best practice theory.

3.1 Public Policy – Tenets of Formulation, Implementation and Evaluation

The point of departure in this study from the available literature on this subject is the emphasis on prioritising the subjective OVC experiences as the starting point for any and all meaningful responses.

A school of thought exists in public policy theory that suggests that for policy formulation to be both meaningful and effective, it must take a "bottom up" approach. Wissink et al (2007: 186-7) suggest that this school of thought is reactionary to the more authoritative "top down" school of thought (that is to say that the "bottom up" approach identifies the weaknesses of the "top down" approach and suggests some alternative ways to counter those weaknesses. Key among these is the recognition that "it is necessary for policies to be 'reinvented' so that they better fit local needs" (Wissink et al, 2007:187).

Another key tenet of the bottom up approach to policy formulation and implementation is the fact that the "voices" of the beneficiaries are given prominence. A qualitative approach is employed here while policy makers in the top down approach will respond to social problems

in a well thought out and rounded way, a lot of the time this approach lacks the input of the subjective opinions of the beneficiaries. This has more focus on a quantitative approach. For instance, in a top down approach "the powers that be" may recognise that there are low levels of literacy among OVCs. The immediate and obvious response to this would be to formulate policy that ensures the enrolment of these OVCs into schools and other literacy programmes. This could be done by making access to these services free to these OVCs or subsidised by government. While this is both noble and beneficial to the OVC it neglects to delve deeper into what (besides not being enrolled in school) could possibly contribute to the low levels of literacy among the OVCs. Reasons for low literacy levels could include psychological issues like depression (which cause decreased levels of concentration), poor housing (light no electricity for adequate lighting to do school work at night) and a non-conducive environment for the proper development of the child (over crowding in the home with a poor emotional support structure) and so on. All these issues contribute to either keeping these OVCs from concentrating while in school or completing homework tasks, etc. which lead to low levels of literacy. It inevitably becomes evident that introducing sound policies that promote literacy alone do not go far in remedying the problems faced by OVCs in the long term.

It is in this respect that the bottom down approach comes to light. By encouraging the active participation of the beneficiaries in the policy formulation process the intricacies of some of the challenges that they face can be exposed and then appropriately responded to. "Policy is a complex, dynamic, multi-level, multi-actor process at formulation, implementation and evaluation levels" (Wissink et al, 2007: 187). There is consensus between the top downers and the bottom uppers that there has to be constant feedback and evaluation between policy makers, implementers, participants and beneficiaries. The sticking point that separates the two schools of thought is that the bottom uppers place more emphasis on the feedback and evaluation form the point of view of the beneficiaries.

The top down approach has been the dominant genre and typically starts from the authoritative policy decision at the centre (top) level of government. "Glitches" within the formulation and implementation process have lead to a rethink of this approach to include questions like; to what extent are the needs of the target group consistent with (the objectives and procedures outlined in that) policy decision; to what extent have policy outcomes and

objectives been attained in the view of the beneficiaries, and; how was policy reformulated over time on the basis of documented beneficiaries experiences?

3.2 Social Welfare Policies and Interventions in Dealing with OVCs

During the first decade of democracy in South Africa, the energies of civil society organisations in the HIV and AIDS sector led by the Treatment Action Campaign (TAC) were largely focused on challenging the government to recognise the scale and depth of the emerging epidemic.

While the government response is a matter of national policy and has always been framed as a 'partnership', clearly the role of individual leaders is critical. Strong, visionary leadership is needed in all sectors to defeat an epidemic that is affecting all sectors.

The government's response emphasizes reliance on communities, but also recognizes the need to provide them with financial support. As illustrated by Gow and Desmond (2002a: 108), this objective was achieved by the establishment and rapid expansion of a means-tested 'child support grant' (Rand 170 per month) for poor children, an 'orphan foster grant' (Rand 530 per month) and a means-tested 'care dependency grant' for children with severe mental and physical problems (HIV-positive children are not included in this category). The first programme expanded rapidly (from 202,000 children in March 2001 to 3.4 million in July 2003). In March 2001, the orphan foster grant covered around 52,000 children, only 20 per cent of the estimated 250,000 orphans at that time. The South African government has extended measures to support orphaned and vulnerable children, and the family networks and communities caring for them. For example, in 2009 it extended the Child Support Grant to all eligible children up to the age of 15 years and has committed to extending this up to 18 years. The Department of Social Development (DoSD) reported at the end of 2008 that 8.3 million children were receiving this grant, with almost half a million more children receiving a Foster Care Grant (FCG). However, there was a backlog at that time of 157 000 applications and a chronic and severe shortage of social workers to process these, monitor foster care and respond to a wide range of other child care and protection needs (Gow & Desmond, 2002a: 109)

The DoSD funds a home-community-based care and support programme that assists more than 200 000 children affected by HIV and AIDS. It also provides social support to child-headed households and assists a network of local child care forums. Other forms of support available to children in impoverished homes include school fee exemptions and access to nutrition programmes (feeding schemes), which are also to be extended to secondary schools.

It is important that there continue to be community initiatives that address the needs of orphaned and vulnerable children and their caregivers. However the gap between need and provision will remain until increasing HIV infection rates are reversed and all of the HIV-positive population are able to access life-prolonging treatment.

Without belittling the efforts of the government to counter the prevalence of HIV/AIDS and to counter the effects that it may have to the wellbeing of OVCs, it has to be mentioned that beyond the roll out of financial grants and very limited financial support assistance to these children and the families that support them falls short.

4. Chapter Four - Methodology

A case study was used in this research process. The reason for selecting a case study over other social research methods that would have been equally well suited is because "case studies allow for a researcher to tell the validity of current knowledge in the specific field of study" (Babbie, 2004: 114). Furthermore, as already pointed out, little knowledge exists that is specifically related to the experiences of HIV/AIDS OVCs and the responses by stakeholders to these experiences. Using a case study to "test" the current body of literature allows for the development of hypotheses that are the starting point for further research. In so doing the body of literature on this subject is increased and at the same time a more detailed study/analyses is done in this particular field.

Qualitative research methods were employed as these were seen to best serve the aims of the study. The researcher made use of a case study to test if the responses to the problems facing HIV/AIDS OVCs are appropriate to the articulated experiences of the HIV/AIDS OVCs from the case study. Data collection was achieved through focus group discussions with the OVC participants and semi structured interviews with other key informants. These include the programme Executive Director, the Project Manager and two peer educators. Information obtained from these key informants was used to double check/verify some of the information provided by the OVC participants. This included information on the OVC backgrounds when they joined the organisation, the circumstances of their orphanhood, family structure, which family members are care givers etc. The focus group discussions centred on six questions (see Appendix C). The primary objective of the group discussions was to gain an understanding of the lived experiences from the OVCs perspective and to establish if current government and community responses are meeting these needs in their opinion. There were two focus group interviews conducted in two and a half hour sessions each. The participants were divided into groups determined by age and not gender; 13-16 year old boys and girls in one group and 17-20 year old males and females in the other.

The composition of the groups was fairly balanced between boys and girls with a slight bias towards more female participants. The total number of participants in the study was 32 with 54% of these being girls and 46% being boys. The participants were selected from the OVC project already established and being run by AU.

4.1 The Case Study – "The OVC Project" at Africa Unite

Africa Unite (AU)

Africa Unite is a community based, non-governmental organisation that aims to promote human rights and empower young adults from diverse cultural, social and economic backgrounds. Africa Unite's activities are based on the philosophy that bringing young adults from diverse backgrounds and working to develop a shared culture of Human Rights will help to discourage delinquent behaviour and promote education, leadership and peace in South Africa. The organisation is funded mainly by private donors and also partially funded by the RSA government through the Department of Social Development. Its offices are located in the Institute for Democracy in South Africa (IDASA) building in the Cape Town CBD.

> *Africa Unite strives towards the achievement of a united and prosperous Africa in which all people live together harmoniously and peacefully.*
>
> (Africa Unite mission statement)

Africa Unite credits its formation to the fact that there was an apparent need for a response to various concerns voiced by young adults living in South Africa. The current reach of the organisation is limited to the Western Cape Province, particularly in and around the city of Cape Town.

4.2 Research Participants and Procedure

In order to obtain a stable and accessible population for the study, research participants were sought from an ongoing project administered by Africa Unite (AU). The organisation runs many of these projects through satellite offices in the specific locations that they target for social development. The particular project in question is run from the Roman Catholic Church, NY5 Gugulethu. It is called "The OVC Project" and it is from this project that a purposive sample was taken. In a manner of speaking, the OVC project was used as a case study to address the research question. OVC participants were purposively selected from between the ages of 13 and 20 years with 32 participants in total. All the children in the AU OVC project (and therefore all the children in this study) have lost one or both parents to HIV/AIDS. These were the only criteria for the selection of participants in this study.

Because these criteria of participants needed for this study match those of the AU OVC project it served the purposes of the research to use the project as a case study.

The focus group discussions and most of the research work were conducted at this satellite office. At this location, it was explained (with the help of a translator) to the OVC participants that the focus group interviews would be tape recorded via a handheld voice recorder and that all our other interactions would be documented for the purposes of producing a final research document. The focus group discussions were conducted and completed in approximately two and a half hours. In addition to the information gathered here, there were several informal conversations and interviews with OVC individuals and groups. There was also limited use of participant observation by the researcher in that there was full participation and documentation of the project activities beyond the research tools used to gather information.

The OVCs spoke in their indigenous home language of isiXhosa with limited use of English. To begin with the general atmosphere was quiet and withdrawn but as the discussion progressed, the OVCs appeared to get more comfortable and the response rate increased. A short debriefing session was held after the completion of the discussion. The taped discussion was also sent off to be transcribed and translated into English text so that it could be analysed using thematic content analysis. The same procedure was followed with regard to the interviews conducted with the various other project participants.

On the basis of my internship with Africa Unite, a relationship of trust developed between the project managers, the project officers, the OVCs and me as the researcher. During the internship I became aware of the ways in which AU was meeting some but not all of the needs of the OVCs. The disconnect between the articulated needs of the HIV/AIDS OVCs and the response by AU as a key stakeholder became the point of departure for an investigation into this subject. And in so doing The OVC Project thus became the case study for this thesis. Formal communication of the study and the intention to do focus group interviews with the OVCs were sent out to the guardians of the children through the project manager and officers at Africa Unite. None of the OVCs or their guardians objected to participating in the research.

Prior to the focus group discussions held with the OVCs, meetings were held with the programme director at AU and the relevant project manager and project officers. These meetings served to re-iterate the purpose and process of the research study and to make clarifications, where necessary. AU recognised the relevance and importance of the research they were being requested to participate in and was happy to make themselves and their resources available for the purposes of this dissertation. Since AU already had a small group of youth and children that matched my selection criteria and also participating in the OVC project, it was decided that all the children would be included in the study.

AU through its project officers and the OVC project manager spoke with the participants in their care, to obtain verbal consent and assess their willingness and ability to take part in the research. This verbal consent was also obtained from some of the OVCs caregivers who participated in a series of parenting workshops that run concurrently with the OVC project at the Roman Catholic Church, NY5 Gugulethu. Finally, the AU project leaders provided a signed consent form for each OVC participant, in their capacity as guardians. An introductory meeting was then held between the OVC participants and the researcher to establish initial contact and to further explain how the research would be conducted. It is important to note here that a lot of the information used to inform the themes later identified was obtained during this and other such meetings that took place between the researcher and the OVC participants. Further to this, all the information gathered was not limited to being provided in or obtained from the focus group discussions alone. There were several informal interactions and observations made that that contributed to the body of information gathered

4.3 Ethical Considerations and Limitations

This research presented a difficult ethical dilemma owing to the fact that it was conducted in the context of poverty, vulnerability and HIV/AIDS – all of which have significant stigma attached to them. Individuals living with these circumstances are at risk of exploitation due to their own compromised position. For instance, that the study participants were recruited from "The OVC Project" at Africa Unite (a strong source of support in the lives of the HIV/AIDS/OVCs). This in itself could imply pressure to participate. This subtle pressure may have existed due to a sense of obligation to the organisation or an underlying hope that participation would lead to added benefits for them. This could perhaps explain why none of the OVCs or their guardians objected to the research work being conducted or their

participation in the study. In the same way, the underlying fear of losing out on the current benefits they enjoy, courtesy of Africa Unite, may have also influenced the OVCs willingness to be involved in the study. Added to this, my position as an outsider (even though I had been attached to the organisation and participated in several activities with and for the OVCs) may have conveyed to the OVC participants that some compensation would result for their participation in the study.

In order to minimise these complications and clearly state my intentions, I presented a letter to the Africa Unite Executive Director describing the research focus and requesting voluntary participants from "The OVC Project". I requested that the project leaders (through their regular channels of communication) explain the purpose of the study to the OVC participants and their care givers (see Appendix B). I stressed that the project leaders convey clearly that no material benefits would be given for participation and that participation in this study would have no effect (positive or negative) on their relationship with Africa Unite or any of the staff. This approach to recruiting allowed for consent to occur between Africa Unite as an organisation and the OVCs, thus preventing the potential pressure to participate that may have resulted from the researcher's direct consultation with the OVCs.

During the interview process I was aware that a great deal can be conveyed through body language and demeanour to facilitate an open and honest conversation. It became crucial for me as the researcher to find common threads in the life experiences of the OVCs through their body language and other non verbal communication. I sat in the circle with them and tried as much as possible to display receptive body language such as leaning forward to show interest, and nodding with verbal prompts to encourage them to share more.

The HIV status of the OVC also posed another unique ethical challenge due to the high levels of stigma attached to it. Even though the study participants were HIV/AIDS OVCs, stipulating their own status was deliberately left out. The reason for this was that this information had no bearing on the aims and objectives of the research. The study aimed to bring to light the experiences of children who have been orphaned or made vulnerable as a result of illness or death to their parents/caregivers resulting from HIV/AIDS. The focus of the study was not necessarily on the HIV/AIDS status of the OVCs themselves. In light of the stigma and negative attention that this study may have attracted for the participants, the

researcher resolved to conduct all the interviews at the project site (the Roman Catholic Church at NY5 Gugulethu), a place all the participants were familiar and comfortable with. This was also a venue that they had been attending for several months prior to the commencement of the study and so it was assumed that they had been able to eliminate or deal with the stigma attached to visiting this location and participating in the OVC project. Further to this, the OVC participants were informed that they could withdraw from the focus group discussion and indeed the entire study at any time. Pseudonyms were also assigned to the participants to guarantee privacy of identity.

During the course of the compilation of the dissertation there remained an ethical dilemma. When compiling the research data it became difficult to form conclusions about the OVCs lives. I as the researcher became aware of the broader implications of the dissertation and this meant that the OVCs needed to be represented in a way that did not underplay their experiences or exaggerate them. If the research findings were conveyed or perceived in either of these two ways it may skew the effectiveness of any responses that may follow. Also, due to my "extended internship" and subsequent use of "The OVC Project" as a case study, I wanted to remain respectful to Africa Unite and the OVC participants. This thesis attempted to find such a balance and to accurately present the life experiences of the OVCs presented here.

Each OVC participating in the focus groups was randomly assigned a number from 1 to 16, in each group, for identification. The identifier was denoted by the letter 'P' for 'participant and then the number (i.e. P1, P2, P3 and so on). Any direct quotes attributed to an OVC were marked by the assigned number identifier, then the focus group they belong to (i.e. 'G1' for the group consisting of 13 to 16 year olds and 'G2' for the group consisting of 17 to 20 year olds). The final identifiers were the gender markers, 'F' and 'M' for female and male respectively. An example of this would be 'P1G1M' for participant one in the 13- 16 years category, male.

4.4 Data Analysis

The data analysis process was started first by having the tape recordings from the focus group discussion transcribed and translated into English. This was done with the assistance of an English and isiXhosa speaking translator. Thematic content analysis was used to analyse the data on the transcription script. This process begun by conducting a read-through, in order to verify the accuracy of the transcribed data. The data was then worked through inductively with the aim of detecting, grouping and classifying unique categories, and eventually main, reoccurring themes. A continuing process of the refinement of categories formed part of the categorisation, to ensure symmetry with the research questions and also to streamline the number and variety of categories and themes. Nine core themes were identified by the end of this painstaking process. They were; negative social economic change; emotional suffering; social isolation; loss of family safety nets; premature entry into adulthood; violation of child rights; survival and coping; the role of external intervention and; stability and the future.

The first part of the categorisation coding process yielded tens of data segments. These were derived from the various participant responses to the focus group questions. The data segments were identified by topics, as illustrated in the example below. The Pseudonyms described above are used to protect the identities of the OVC participants.

First level coding
Identification of topics from data segments

Data Segment
P1: *things are not the same and they are not good. I don't have my parents . . . I don't have anyone who I can run to . . . when mum was there I was getting what I wanted it has changed because this time I cannot demand, I've got no one who I can call mummy . . . who can make me feel as if I am the child . . .*

Topics Identified
a. Being without a provider
b. Feeling abandoned
c. Being without parental/motherly love

Each data segment was used to illustrate a particular concept, experience or event for the respondents. Once this process was complete, the data segments were reviewed, to identify similarities in the responses. Topics with similar ideas or issues were then grouped together under a category and assigned a label, as follows.

For instance, the topic "being without a provider" would correspond with the category label "negative socioeconomic change". In the same way, the topic "feeling abandoned and being without parental/motherly love" would correspond with the category label "emotional suffering".

2nd level coding

Second-level coding involved re-visiting the categories and topics in order to develop and identify the nine themes referred to above. For the ease of identification and documentation, the themes were assigned codes (i.e. the actual theme acronym).

The topic "being without a provider" along with "changed living conditions, family harmony disturbed, negative change in living conditions: no amenities and ill-treatment; home comforts no longer available; insecurity" and several others were assigned the category label "negative socioeconomic change". The theme identified for this category (to include all the topics highlighted by the respondents) is also "negative socioeconomic change" and the code for this theme is "NEC".

The same two levels of coding and thematic content analysis were used to identify the nine themes form the transcribed focus group interviews and the other information sources.

5. Chapter Five – Findings and Discussion

5.1 General Comment

Data analysis from the focus group discussion revealed that, for the most part, there is consensus among the OVCs as to what issues they struggle with and what their experiences of day-to-day life are. Through a process of refinement, and reiteration, nine themes were identified, in response to the overall research questions. The themes are; negative socio-economic change, emotional suffering, social isolation, loss of family safety net, premature entry into adulthood, survival and coping, the role of external intervention, violation of child rights, and stability and the future.

The children spoke about their lives and some experiences that they had had during the illness and since the loss of their parent(s). During these discussions, some of the children admitted to knowing that their parents had died of AIDS, while others said they suspected that was the case, because their parents had become very frail and been progressively deteriorating until their eventual death. As part of the analysis follow-up process, the identified themes were later verified with the participants in order to confirm that a correct interpretation had been done of their experiences. On the return visit to the OVC project at the Roman Catholic Church NY5 Gugulethu it was found that many but not all the original research participants were still actively involved in the other project activities (including the weekly sexual reproductive health workshops and after school extracurricular programmes among others).

As mentioned above, interviews were also conducted with the OVC project leader's as well. This was done in conjunction with rudimentary forms of participant observation in the project activities. The information gathered from these interviews and interactions has also been included in the thematic content analysis and it was used to inform the main themes identified.

5.2 Themes

5.2.1 Negative socio-economic change

The socio-economic impact of HIV/AIDS is perhaps the most noticeable impression from a first glance. All of the children who participated in this study live in Gugulethu Township and other nearby surrounding areas. These children are advantaged in comparison to children who may become gang members, engage in criminal activities or live on the streets. That said, even for these "lucky" children, it is important to recognise that the death of their parents/care givers leads to a significant change in their life styles. The period between their parent's death and their entry into a new family and home situation is for the most part challenging.

All the children who were interviewed experienced interruptions in their school attendance either during their parent/caregivers illness and/or after the death of the parents/caregivers. Ailing parents were no longer able to pay school fees or make available necessary school provisions enabling their children to attend school; hence most of the children had to leave school for some period of time. Foster & Williamson (2000: 14), speak about this decision by parents for their children to discontinue school attendance. They attribute it to various reasons such as the reallocation of funds to pay for medical expenses; the need for older siblings to look after younger siblings at home while the parents are ailing or, to take over other household chores. This happens more frequently to girls than boys.

The parent's inability to provide, was also felt in the absence of basic necessities such as food, security and so on.

> ....*Maybe you find that you have to go and ask others for food; your heart just starts to feel heavy...and all that and you start to wish that your father would just get better... Okay...you know it's different when your parents are alive and well... that with everything you feel free, you enjoy life and all is good. Even eating is a pleasure. But once my parents died, everything became difficult, from going to school, eating and even enjoying life – everything was difficult... P7G2M*

The situation is further exacerbated by the issue of poverty. The majority of participants came from families that were not necessarily affluent and that can in fact be described as poor and

worse still, impoverished. The scarcity of savings to cushion unemployment, the absence of medical insurance, the lack of economic/job security, poor housing and low incomes are indicators that these families can best be described as lower class. Hence when the main breadwinner becomes ill the phenomena of diminishing wealth arises; medical and other expenses increase, while the ability to generate income and the capacity to work, is decreased. As a result of this increasing poverty, children could miss the opportunity of acquiring an education and perhaps lose the chance to learn a trade.

5.2.2 Emotional suffering

The emotional impact of parental loss is still quite keenly felt, especially among the younger participants who showed that feelings of extreme hurt and pain were still present as was evident in their body language (their voices trembled as they spoke and they slowly shook their bowed heads from side to side as well). Throughout their narratives, participants repeatedly expressed feelings of abandonment and a lack of love in their new home/living environments. They also relayed feelings of being isolated, feeling unsafe, and being apprehensive without the security of their parents. Other difficult emotions that they spoke about were sadness and hurt, pain and disbelief and, feeling stigmatised. Janoff-Bulman and Berger (2000: 35) speak about the loss of invulnerability which the children experience, as being a part of "the aftermath of extreme negative events". The realisation that something as intense as losing their parents could happen to them leaves them feeling defenceless.

Janoff-Bulman and Berger go on to suggest that more than adults, children begin to rely on what they know; their homes, their families and their social networks, which they see as permanent and reliable. They form attachments which allow them to feel secure and give them the freedom to explore the world from a stable base that they feel anchored to. Most children learn the inevitability of change when they are older and better able to deal with the implications, as they mature. These children however, did not get the chance to learn about how life changes and develops through the cycle that humans have come to accept as normal. This unexpected loss of invulnerability may account for their extreme feelings (Janoff-Bulman & Berger, 2000: 39-40).

> *As for me from when my parents passed away, I don't see anyone to love*
> *me, as the way my mother usually used to love me. And some times when I*

> *sit down, I can't believe that my parents passed away…and I've got no-one*
> *who can make me feel, who can make me feel as if , I'm, I'm the*
> *daughter…*P9G2F

The effects of early childhood vulnerabilities, due to loss of their parents, could have a lasting impact on these children in later life (Raphael & Dobson, 2000: 51). This is already compounded by their lack of academic achievement. Some might argue that the child's perception of abandonment and isolation does not necessarily reflect reality, nor does it represent the deliberate actions of the parents. However, some children understand their parent's death and illness as turning away and leaving them to fend for themselves. The expectation is that sick parents, will get better; death is not an option. While on some level they can articulate that the death is not in fact deliberate and their parents are not at fault, they still experience it as negative. Notwithstanding the 'facts', it is the child's expressed experience that is critical. Over time, as with most people, these OVCs have learned to master their grief.

> *…When she died, it hurt a lot, because I thought that maybe she would get*
> *better, but she didn't….The way I felt was while they were alive I was just*
> *happy and all was well; but when they began to get sick, my heart began to*
> *feel 'hard'…* P3G1F

Several of the OVCs articulated their lack of connectedness to people that cared for them after the demise of their parents, and this appeared to have had an impact on their perception of their own self worth. In this regard, a number of the children questioned their usefulness in the light of their parents' death, expressing feelings of helplessness and being without hope.

> *I did not feel good about what was happening, I just used to feel very*
> *bad…I can't find words for it…as though maybe I should not have been*
> *born to this earth, maybe God should not have made me. I used to ask*
> *myself, what purpose I had on this earth…especially with what was*
> *happening… perhaps I should not have been born…*P11G2M

Unfortunately, these OVCs' narrative suggests that the loss of their parents has disrupted the natural flow of their lives, and left them without direction and significance. And so they question their worthiness in a world without parental protection. One participant communicated how as a result of frustration in the past, he had had bad thoughts. Another spoke about feeling as though there was nothing to live for.

> *When I was feeling that way, and someone said something, I sometimes felt as though I could hurt them so badly...sometimes maybe even kill them... I feel so frustrated...I have even given up completely at times, not caring what happens to me...I feel so heartbroken...*P1G2M

It would seem that in many aspects of their lives, the children have begun to find ways of coping; however, it is with some difficulty that they are able to engage with their feelings. This is particularly difficult in the face of multiple family loses.

> *My younger brother died first, then my parents. I am the only one left... when people tease me about being an orphan, I don't mind... I don't really feel anything.* P6G1F

The environment they are in, and the well-meaning extended family members who are their current guardians, have done their best to provide the basic needs however, according to some, their efforts still fall short.

> *My aunt has made me to survive, she is keeping me... but she cannot give me the love which my mother used to give me, but she is trying to give me all the love that I need.* P13G1F

5.2.3 Social isolation

The participants spoke about feeling cut-off from their familiar social contacts, believing that they were alone, without anyone to rely on. All the OVCs were left in the care of extended family members after their parent's death and sometimes during the course of their illness. In some cases, the experiences reported were difficult; with participants often narrating incidences of negative treatment received in these homes. Results also indicated that children

are facing rejection and being neglected by family members who previously showed them love and concern. Some of the children, who went to live with extended family, reported being subjected to ill-treatment from their guardians. In some instances these children felt that they were regarded differently from the other children in the new household. According to them unfair treatment and disciplinary measures were employed. On the issue of unfair treatment:

> *…after school I am hungry but they do not give food, they say there is not enough food but the others are given.* P2G1M

Few of the children indicated a continuing positive relationship with their relatives. In South Africa as in most African countries, and indeed other countries all over the world the expectation is that the extended family steps in to care for children that become orphaned. This informal adoption is a matter of course in most instances. However, the increased reliance on these extended family structures under these poor and difficult circumstances, coupled with the ever decreasing number of relatives who are able to fulfil this role, has resulted in this support system becoming more difficult to access. According to UNICEF & UNAIDS (2006: 2), in South Africa, the HIV prevalence rate among adults aged 15-49 years, is 17%, with mortality rates, estimated at about 96 000, per annum. Consequently, the number of adults who will be available to look after orphans will remain low and children will continue to have the experience of being "neglected and rejected" by the very adults that are expected to protect them.

Furthermore a supposed well-meaning effort to shield OVCs from the trauma of illness only succeeded in having the opposite effect. This practice is also a mainstream occurrence wherever possible. One of the OVCs spoke about external interventions that sought to separate her and her sibling from their ailing mother. She was particularly hurt by these efforts as she felt that she could have helped nurse her mother through her illness, and thereby maintain some connection with her before she died. She was left feeling excluded.

> *…my aunt, didn't want my mother to be coming to see us…she said we are not supposed to see her because she is sick. My aunt said she would visit*

mum and tell her that we are fine...since my mother was sick I wanted to take care of her. P7G2F

It was found that the OVCs participating in the Africa Unite OVC project felt further separated from the outside world as they (by their own accounts) reportedly had few, if any friends outside the confines of the OVC project and the other Africa Unite projects. They attributed this inability and lack of willingness to pursue friendships with "outsiders" to feelings of exclusion from "normal children". It would appear that orphan hood has condemned these children to a future of isolation and with little hope.

5.2.4 Loss of family safety-net

The loss of family and what it represents has had a significant impact on these particular HIV/AIDS OVCs. Most of the research participants made some reference to the changes experienced when they were no longer part of their biological nuclear family units. The dislocations and deprivations that the children experienced meant that they have lost the familiar and can no longer access the protection that a familiar family environment provides. In this way it is demonstrated that children begin to experience the effects of parental illness and death from HIV/AIDS long before the actual death, and also long afterwards. Social stigma, gradual impoverishment, and stress related to possible increased responsibility may start and progress during the illness. This presents a contradiction with regard to the point made above where it was suggested that keeping children away from their ailing parents is detrimental to the happiness of the child and that they feel that it isolates them socially. Even though some children may prefer to be close to their ailing parents, it is in the best interest of others to be shielded from witnessing their parents' deterioration. The distinction between the two "types" of children has to be very carefully determined so that decisions can be made accordingly.

While the death of a parent is in itself difficult as it denies the child, among other things, the potential for being nurtured and protected by someone who loves them; it is however the subsequent life changes within the home that seem to have affected the children even more. When both parents die, children are unlikely to remain in their parental homes and may get split up among various relatives, thereby compounding their losses. They may be further denied access to other familiar social networks such as school, friends and community. Some

of the children spoke about having moved to the Western Cape Province to live with relatives after one or both their parents succumbed to their HIV illness in other regions of the country.

In defence of the extended foster families that take on the parenting and care of these HIV/AIDS OVCs, the separation of OVCs is a strategy employed in order to divide the material burden and responsibility of care. We must bear in mind that the families most affected by this double pronged attack are poor with limited resources thinly spread out and stretched very close to the limit.

With that said, it must also be mentioned that a child interacts primarily within a nuclear family unit, and then later, within the immediate community of child-care, school, health professionals and the wider community. Thus a child's core well-being is governed by the quality and support provided within these interactions. At another level, a child interacts within a wider community with culture, belief systems, attitudes and social policies (Pryor & Rodgers, 2001: 76). Conventionally it follows then that in the absence of a child's biological parents, the responsibility of care moves to the extended family. This care is supplemented by schooling systems, members of communities and other custodians and providers of social services. Strangely though, for these particular OVCs, institutional care seems to be their most sought after and desirable option as it offers a relatively high degree of protection and structure.

> *...I like how it is here in the project and I wish we could just stay together all of us...they should make a place for us to all stay together because we understand each other...where we stay they do not understand us...* P14G1F

This is especially true where the traditional safety nets offered by extended family are becoming less accessible. However, past research on the institutionalisation of children has long found a number of challenges including issues related to poor/detrimental child development (caused by, among other things, inadequate staffing levels, staff attrition and the lack of auditable standards in these institutions). As the children become adults and have to leave these "homes", they continue to be at risk because of the stigma of growing up in these environments, and could therefore become repeat victims of society's unwillingness to accept

them. Be this as it may, it is still important to note that this is an option that the OVC's themselves consider highly as a means to ensure their development and well being.

5.2.5 Premature entry into adulthood

The issue of taking on the responsibility for younger siblings was a recurring theme. Older OVCs were often tasked with the role of looking after other nuclear family members because the primary caregiver was no longer alive or well enough to be able to fulfil this role. A gradual shift in responsibility begins to take place when parents start to get sick. A role-reversal may begin to occur where the traditional roles of caregiver and receiver are exchanged. In more extreme cases, older siblings become heads of household and become fully responsible for those left in the home. This was certainly evident in the some of the experiences shared in the focus group discussion.

> *I used to miss school so that I can take care of my mother and help her to wash . . . nowadays I must keep my young sister and make sure she can eat something in a day . . . if I go to school there will be nothing so I must look for job and get money …*P12G2F

5.2.6 Violation of child rights

The violation of child rights though not spoken about as much as perhaps other concepts, still represents an important aspect of the lives of the OVCs. In 2005, Sub-Sahara Africa had approximately 48 million working children under the age of 14 years, most of them in an unregulated, illegal informal sector. (ILO, 2005: 8). Traditionally, children's involvement in economic activity, especially in rural communities, was based on customary practices where the work of children was age appropriate and designed primary as a learning tool, and as part of the child's community engagement. So chores like collecting fire wood or water from areas located far away from the homestead are common place in many rural African communities. However, in this instance, the issue under discussion is the experience of the impoverished urban HIV/AIDS OVC.

Over time, and due to industrialisation, rural to urban migration, poverty and so on, the type of work that children engage in has become inappropriate and exploitative in many instances. The work that children now do is more about economic survival, and possible exploitation,

than cultural participation. For instance, some of these OVC's were engaged in employment such as ferrying goods on wheelbarrows (often too heavy for them to move). This work was backbreaking, harmful, affected their physical and mental health and, detrimental to their natural development. However the OVC's still made attempts to perform these jobs as they were not in a position to pick from alternative choices. Worse still these OVC's may be forced into engage in economic activities because they are made to believe that they must contribute to the material support of their new households.

> *When the money was all spent, we started to wonder how we would survive.*
> *We decided to take my father's old wheel burrow and start a small business.*
> *We would use it to carry people's parcels for them in the township.* P3G2M

With regard to pressure from their extended family members and care givers to contribute materially to the household, the OVCs said that they had been mistreated and abused.

> *For me when my father died, and we moved to my auntie, the other children*
> *would tell me that the house was theirs. Things got worse and worse, they*
> *were not treating me as my parents used to treat me so we never got on very*
> *well. I did not eat or sleep properly and I was not free. When I want more*
> *food they say you must work for food so I would do small jobs for people for*
> *some money.* P5G2M

The reality of "adoption" or rather taking on the responsibility of care of OVCs, especially in the economic circumstances of many of these families, is that just one extra mouth to feed has a significant bearing on the limited resources (financial and otherwise) of the new care givers' household. Often, the assumption of the responsibility of OVCs is less about volunteering for the job and more about a sense of obligation. However, it is the opinion of this researcher that, in line with cultural practices such as 'Ubuntu' (the concept of humanity through community, shared experiences, responsibilities, burdens and joys), extended families would like to help, but, they find themselves reluctant to do so because of the increased strain it places on their already stretched resources. Kielland and Tovo (2006:46), report that in some southern African countries orphans are often taken in by relatives for "…commercial gain, either for their labour or for grants made available to orphan

caregivers…". Girls especially, are utilised as domestic help, and are thus more likely to be taken in by relatives. Thus children who already have to endure orphan hood, continue to be exploited at the hands of those who should be assisting and protecting them.

5.2.7 Survival and Coping

The experiences of these OVCs, has placed them in special communities of people in similar circumstances (such as the Africa Unite OVC project). This in itself has been positive outcome in ensuring their survival and equipping them with some of the skills required to cope. Research supports the understanding that difficult life circumstances and events, are known to bring people with similar experiences together in supportive social networks (Janoff-Bulman & Berger, 2000: 33) notwithstanding whether it is perceived as positive or not.

The OVCs articulated what are often described as healthy coping techniques that they have employed to deal with the loss of their parents. These included interaction within their community of friends; distraction techniques such as reading, listening to music, singing and participating in extracurricular activities such as the after school programme at Africa Unite. The old adage 'a problem shared is a problem halved' seems to hold true for the girls in the study. While institutional living has often been criticised because of a myriad of problems, it has got its merits and the OVCs have recognised it as crucial to their survival. They expressed a strong inclination to this kind of response as the most appropriate in dealing with the problems that they face.

> *If they could just build us a big house where we can all live together as OVC, it would be nice... I feel good when I am with these people [looking around at the other OVC participants in the Focus Group discussion].*
> P10G2F

Having had similar experiences of loss has allowed the OVCs to access people who understand and can relate to the difficulties that they have endured. The importance of this support structure has been alluded to earlier in the literature review.

I don't, I don't like being alone and thinking about what I've gone through, I like being with friends. So when each one is telling stories, I don't think about them [deceased parent(s)] very much. Yes, when I sit down, I like listening to music a lot, I listen to music or I sit with my friends just talking.
P10G2F

A few of the OVCs explained that they had other coping strategies which would be described as both detrimental and dangerous. Their coping strategies allowed them to survive and cope from day-to-day. They admitted to taking alcohol and other substances while trying to deal with their respective losses and admitted to engaging in sexual activities as well. In many cases, substance abuse provided some respite from the anxiety they felt about their situation. As a consequence of substance abuse, higher levels of bad behaviour and delinquency occurred. It did not appear as though they abused substances merely for the fun of it, but in many cases, they saw it as providing some reprieve from thinking about their situations. Bad behaviour and delinquency as a means of coping came about as a consequence of substance abuse.

When I was sad what helped me to survive was glue…. I would try very hard to find work so that I could make some money to buy glue to smoke so I would start to feel better. When we smoked the glue we would steal things from shops and cause problems around [the neighbourhood]. P16G2M

In their current environment (i.e. the Africa Unite OVC project), the OVCs mentioned that they have adapted to healthier coping strategies. This they say is as a result of the feeling of security that AU as an institution offers them. It is important also to acknowledge the personal resilience that each one of these OVCs exhibits. Not all children survive and thrive in institutions. One of the girls had been a participant of the OVC project during a previous cycle, but she had run away and engaged in delinquent behaviour until she fell pregnant, at which point she returned to the OVC project for a second time. Despite the various and sometimes questionable methods used to cope with their individual experiences, the children continue to survive.

5.2.8 The role of external intervention

The resources of family and community support structures have been tested and become stretched due to what is seen by many as a crisis in Africa in general and South Africa in particular. Inadequate food security, land issues, public health problems, poverty, HIV and AIDS, among several other reasons are some of the major contributors to this uncertainty. Reliance on community security structures is slowly becoming a thing of the past; thus those most at risk such as OVCs have to look to other sources for help.

Perhaps the greatest contributor to the survival of these particular OVCs has been the intervention of non governmental organisations, faith-based organisations and well-meaning individuals. The inadequacies of an effective social security system, has placed the responsibility of caring for OVCs largely, on the shoulders of the private sector. Africa Unite as an organisation and through its various projects has nurtured the children and provided basic needs such as food, education and learning support, structure and support, and security. They have also given the participants the opportunity to attain their fullest potential. This was and continues to be achieved through parallel AU projects such as the Sexual and Reproductive Health workshops, the After School Tuition programme, Drama and Dance classes and so on.

> *For me, what I found that is good is that they [Africa Unite] help us with our school work; they help us with many things. We learn about HIV and how to be careful. They want us to be able to help others in the future; so we can show them too, what life is like…*P12G1F

The HIV/AIDS epidemic has given rise to many programmes and projects such as the Africa Unite OVC project. These initiatives are relatively small in number, when compared to the increasing number of OVCs. The economic constraints that affect the majority of the population are making it more difficult for extended families to continue the practise of absorbing OVCs into their own families; hence the numbers of OVCs will continue to rise.

On a wider scale, multi-nationals such as The World Bank Global Fund and various UN agencies in conjunction with the South African government and the private sector are

involved with reducing and arresting the spread of HIV/AIDS. There is a need for these various actors to centralise and co-ordinate such efforts around the country. A recent USAID (2007: 11) report indicates that while mortalities continue to increase, new cases have begun to fall off, as risky sexual behaviours have declined. Awareness and education campaigns mounted largely by NGO's and the private sector appear to have been well received and absorbed by many South Africans, and the results are slowly beginning to show. However, the reality is that while public programs are making some headway, the pace is slow and will take some time to have any real and significant effect. In the meantime, organisations such as Africa Unite are continuing their commitment to helping OVCs, by providing basic Necessities

While appreciative of the continued efforts made by Africa Unite, the OVCs still feel that more can and should be done to address their plight. One of the incentives that AU used to entice participation in the project was to hand out grocery shopping vouchers to the OVCs for monthly attendance. At some point during the course of the project cycle, AU decided to substitute the shopping vouchers with food parcels. There was mixed reaction to this change by the OVCs. However the resounding sentiment was that some found the shopping vouchers to be more useful than the food parcels.

> *There is food at home but I need some things for school. They must give us*
> *the Shoprite thing [food voucher] again so that I can buy things for school.*
> P15G1F

5.2.9 Stability and the future
The current environment and the positive experiences that the children are encountering are allowing them to envision a future for themselves. The OVCs feel that there is a real possibility that they can complete their education and become self-reliant. This, along with a stable and safe environment (which is being provided by their guardians and well wishing organisations such as Africa Unite), have been identified as being uppermost in their current ability to survive.

While education and a comprehensive and all inclusive support structure have been singled out as important, there is another element that has been voiced almost unanimously. The

children's individual life experiences and the actions of well-wishers have left them wanting to 'pay it forward' through assisting others, as soon as they are able.

> *… I want when I grow up, when I finish school, I should start helping other people…they should not feel bad like this and I must help them to be happy* P4G2M

The difficult life experiences that the children have had, and the fact that they are alive with the possibility of successful futures, puts them among the survivors; and the children are cognisant of this. They have come to an understanding that while life and society may continue to present them with various obstacles, they have developed personal strength and are therefore equal to the challenge; their own stories give testament to this. In light of this knowledge, the OVCs in this study have all expressed their desire to help others whose lives may mirror theirs.

> *I want to become a social worker… I want to help other children, as others have done for me. So I am very grateful to Africa Unite, what they have done for me, because I have a hope in life.* P4G1F

The above analysis and examples of the content of the focus group discussions establishes that the objectives of the research have been achieved and demonstrated. A rudimentary analysis of the data collected leads to the following broad but pertinent conclusions; there are similarities on the lives experiences of HIV/AIDS OVCs across variables such as age, gender, circumstances of orphanhood, vulnerability etcetera. This is not to say that there aren't any notable differences between the age groups, the gender groups and even between the individuals. Though the lived experiences of each individual OVC has its uniqueness the commonalities, as expressed in the 9 themes discussed above, indicate a shared experience with regard to several aspects of life as an OVC.

It is also important to point out that while the 9 themes drawn from the data highlight negative experiences and aspects of life as an OVC, there have been several strides taken in recent times that have yielded positive results and feedback. Key stake holders such as the international community, national government, civil society organisations and the affected

communities themselves continue to make headway in improving the conditions for, ensuring the rights of and securing the basic needs of OVCs. But if these negative experiences are being expressed in light of all the efforts being undertaken by stake holders, it follows that logic should lead to an investigation of where and how efforts in the current responses to OVCs fall short – effectively, what are the gaps in the responses to HIV/AIDS OVCs.

6. Chapter Six – Discussion on "Gaps" in the Responses to HIV/AIDS OVCs

So far the information gathered from the HIV/AIDS OVCs participating in the Africa Unite project is comprehensive in respect of the fact that nine distinctive themes have been identified. These nine themes are the representation of the lived experiences of the HIV/AIDS OVCs in this Gugulethu case study. It goes without saying that some of the lived experiences of OVCs wherever they may be, are universal. However, it is also important to note that not all the lived experiences of OVCs are the same. The differences are dependent on a number of variables such as previous socio-economic situation, current socio-economic situation, age, level of education, gender and so on. It is for this reason that the case study described above was selected to test the effectiveness of the responses of the lived experiences of these particular OVCs.

This is not an attempt to expose gaps in responses to OVCs and then arrive at the brash conclusion that any and all responses are both ineffective and inadequate. Rather the aim is to highlight the fact that as best as possible OVC cases need to be isolated (in terms of surrounding circumstances) so that appropriate, "tailor-made" efforts to respond can be proposed.

This chapter gives an overview of responses to HIV/AIDS OVCs by key stakeholders. The aim is to point out where these stakeholders fall short by comparing how and what they respond to, in relation to what the OVCs have prioritised as their concerns.

6.1 International Community and Government

International community

Descriptions of the impact of the HIV/AIDS epidemic on children in Africa first appeared in conference and research papers in the late 1980s. The articles at that time provided estimates of the future scale of the orphan epidemic and described community-based assistance

programmes in place at the time. The World Health Organisation (WHO) and UNICEF were instrumental in disseminating research findings, documenting the problem, analysing responses, and proposing remedies. However, the early writings were not translated into concerted international action with the result that, during much of the 1990s, the problem of children affected by HIV/AIDS was given low priority by United Nations (UN) agencies, development organisations, international NGOs, research bodies and governments in affected countries. Instead, programmes to support vulnerable children were developed by local groups and organisations, and slowly attention was drawn to the worsening situation of children living in communities affected by AIDS.

As mentioned above, the 1997 *Children on the Brink Report* by the United States Agency for International Development (USAID) catalysed a change in responses by the international community to children affected by HIV/AIDS. This report documented the scale of the impending orphan crisis and proposed intervention strategies. During the past decade, international support for responses to the HIV/AIDS crisis has increased significantly, with some of the financial resources being earmarked to assist children and their families. These resources are being mobilised by USAID, the World Bank's Multi-Country HIV/AIDS Programme for Africa (MAP), the Global Fund, the British Government, and some of the larger international NGOs, among others. (USAID, 2007: 12 - 13)

At the June 2001 *United Nations General Assembly Special Session (UNGASS) on HIV/AIDS,* governments from around the world drafted and endorsed the *Declaration of Commitment on HIV/AIDS: "Global Crisis – Global Action"*, to fight the epidemic. This Declaration included a set of national strategies and financing plans for combating HIV/AIDS and, with regard to children and HIV/AIDS, the following time bound goals were agreed:

- Reduce HIV prevalence by 25 per cent among young people (aged 15 to 24) in the most affected countries by 2005 and by 25 per cent globally by 2010.
- Ensure that by 2005 90 per cent, and by 2010 at least 95 per cent, of young people aged 15 to 24 have access to the knowledge, education, life skills, and services to reduce their vulnerability to HIV infection.

A review of these commitments in 2006 found government progress slow in rolling out treatment and care for people infected with HIV/AIDS, as well as a lack of political will from countries in setting clearly defined targets and timeframes.

UNAIDS is the lead agency in the global fight against HIV/AIDS. Through consultative processes, it recently generated two frameworks:

- The "3 by 5" initiative was launched in 2003 together with the World Health Organisation. The aim of the initiative was to ensure that three million people living with HIV/AIDS were treated with anti-retroviral drugs in low- to middle income countries by 2005. It was agreed that this was a step towards the goal of making universal access to HIV/AIDS prevention and treatment accessible for all who need them. While some countries have overshot their targets (e.g. Botswana), others are lagging far behind, especially in the provision of Anti-Retroviral Treatment (ART) for children.
- The "three ones", a landmark agreement promoting universal coordination in the fight against AIDS, was adopted at a meeting co-hosted by UNAIDS, the UK and the USA in 2004 to strengthen national AIDS responses led by the affected countries themselves. The "Three Ones" principles endorsed are as follows:

  1. One agreed HIV/AIDS Action Framework that provides the basis for coordinating the work of all partners;
  2. One National AIDS Coordinating Authority, with a broad-based multisectoral mandate; and
  3. One agreed country-level Monitoring and Evaluation System.

The initiative was motivated by the fact that some AIDS programmes are developed in isolation by well-intentioned donors, non-governmental organisations and others. Governments of heavily-affected countries often have to deal with confusing demands to show progress. A recent UNAIDS report on the "three ones" outlines specific pointers to donors on how they can contribute to effective country-level and global responses to HIV/AIDS.

Added to this, several international agencies commenced a consultative process in 2000 that led to the development of *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, published in 2004 by UNAIDS, UNICEF, and USAID. The Framework, endorsed by more than 40 agencies, provides the broad range of stakeholders from all sectors of society with five overarching strategies to improve the care and protection of vulnerable children. This is the most significant and coherent strategic document to date, outlining a multi-sectoral approach to supporting children affected by HIV/AIDS. The five strategies aim to:

- Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support; Mobilise and support community-based responses; Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration, and others;

- Ensure that governments protect the most vulnerable children through improved policy and legislation, and by channelling resources to families and communities;

- Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children and families affected by HIV/AIDS.

In September 2005, UNICEF and UNAIDS launched a call to action: *Children – The missing face of AIDS*, advocating a four-point plan, the so-called 4 Ps, as follows:

1. Prevent mother-to-child transmission
2. Provide paediatric treatment
3. Prevent infection among adolescents and young people
4. Protect and support children affected by HIV/AIDS. (The five strategies of *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* are included under this point).

Rapid developments are taking place on the international front. For example, more than 250 documents (published papers, reports, reviews, advocacy documents, etc) were produced during 2004, 2005 and subsequent years. In addition, new impetus has been given to activities in the field through meetings convened and the release of several key documents during the last year. Examples of initiatives taking place include the following:

Understanding the scale of the epidemic and appropriate actions through consideration of the number of children affected by, the nature of the impacts on children, and the long-term effects of orphaning and other forms of social distress occasioned by HIV/AIDS on children's growth, health and well-being. The consultation of the Global Partners Forum in London 2006, led by UNICEF identified key actions required to eliminate barriers to taking to scale effective services and programming for children affected by HIV/AIDS. Recommendations were made in six priority areas: (i) elimination of school fees; (ii) birth registration; (iii) community mobilisation and capacity strengthening; (iv) family support; (v) widespread use of Cotrimoxasole (an ART); and (vi) monitoring and evaluation.

The importance of scaling up responses to match the extent and severity of the problems affecting children. In March 2006 Harvard University announced a two-year Joint Learning Initiative on HIV/AIDS and Children to bring together the required momentum, knowledge, and experience to scale-up responses to support children and their families. Several teams of multi-disciplinary experts, field managers, donors, government representatives, and others, drafted recommendations for action at the global and national levels on the following thematic issues: child survival and paediatric AIDS; family resilience, care-giving and demographics; health, education and social welfare; the economics of providing for children; and rights, protection and participation.

Prioritisation of interventions for infants during their critical stages of growth, development, and socialisation, including uninfected children born to mothers living with HIV/AIDS. UNICEF is instrumental in driving this initiative and area of focus forward.

Paediatric care. Treatment for Children Living with HIV/AIDS (CLHA), including the effectiveness of the drug Cotrimoxasole for opportunistic infections, the need for antiretroviral formulations for children, adherence to medication, and psychosocial care for

children living with and receiving treatment for HIV/AIDS. In November 2004, WHO and UNICEF convened a technical consultation on ARV formulations, whilst in January 2006 UNICEF hosted an international meeting on *Paediatric Care, Support and Treatment: Programming Framework Consultation.* The Global AIDS Alliance produced an advocacy report in 2006, entitled *Children left behind: Global stakeholders failing to adequately prevent or treat paediatric AIDS.*

Psychosocial care and support for children and families affected by HIV/AIDS, and investigating commonalities with approaches used to address children affected by violence, poverty and other forms of adversity.

Supporting families and community-based initiatives and getting additional resources to affected households and communities on the ground. The Firelight Foundation has developed examples of good practice in supporting small community initiatives and their vision is articulated in *The Promise of a Future: Strengthening Family and Community Care for Orphans and Vulnerable Children in Sub-Saharan Africa*31. The importance of family-care, as opposed to institutional-care, for children without parental support has been described in several reports.

Rights-based approaches and the important role of unencumbered access to education, health care, and civil registration in protecting the development of children affected by HIV/AIDS. Research in this area has focused on access to education and research on entitlements to social security and health care provisions.

Social protection. Economic strengthening of affected households and growing support for cash transfers in the form of pensions and grants, as a mechanism for addressing the combined impacts of HIV/AIDS and poverty. UNICEF's Regional Office for East and South Asia commissioned papers on related topics, and UNICEF New York hosted a meeting in 2005 to consider the role of the state and social welfare in strengthening responses to children affected by AIDS. Conditional cash transfer programmes to assist children and families affected by HIV/AIDS have been piloted and/or planned in Malawi, Zambia, Kenya and South Africa.

The critical need for **monitoring and evaluation** structures and systems to ensure that the most promising models are extended and scarce funds are not spent on interventions with limited impact. UNICEF, UNAIDS, USAID, the World Bank, Save the Children, and others have developed a country-level monitoring tool.

By and large international community responses to the HIV/AIDS OVC crisis were forecasts and projections. Much of the "response" was and has been in documenting the extent of the HIV/AIDS OVC problem and then to set plans and guidelines to counter it. The gap exists in that fact that there is no planned, concerted effort towards the practical roll out of actual response initiatives.

In this regard, international responses can be scaled down to regional responses to HIV/AIDS OVCs. This is done to try and establish if the situation that presents here functions with fewer gaps. In many countries, with some notable exceptions, government response with respect to children affected by HIV/AIDS has been slow and ineffective. Poverty Reduction Strategy Papers (PRSPs) were introduced in 1999 to support national efforts to formulate effective growth and poverty reduction strategies. Together with National Strategic HIV/AIDS Plans (NSPs), PRSPs are intended to include links between HIV/AIDS and poverty, the role of communities, and the support of orphans and vulnerable children. However, even though the vulnerability of children is mentioned in a third of PRSPs and NSPs in Africa, not a single country (except Senegal) budgeted resources for activities to care for and support these children - suggesting that even where the issue was identified, there was high risk of policy slippage with interventions for children falling off poverty reduction agendas prior to their implementation.

Governments in Sub-Saharan Africa have generally had limited involvement in the provision of services supporting vulnerable children, although South Africa, Namibia, and Botswana have developed statutory social support schemes that serve important safety net functions for children, including those affected by HIV/AIDS. Some governments, including Malawi, Namibia, South Africa, Zambia, and Zimbabwe, have conducted national situation analyses, established policies for orphans and vulnerable children, as well as establishing coordination mechanisms and legislation to protect and support orphans and vulnerable children, thus indirectly contributing to reducing stigma and discrimination, and promoting children's

wellbeing. However, despite being signatories to the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child, there is little evidence that most states with significant epidemics are addressing the impacts of HIV/AIDS on children. Only 13 per cent of countries in Sub-Saharan Africa had a national policy on orphans and vulnerable children by 2003 (UNICEF, 2007: 13) The recent UNICEF led Rapid Assessment, analysis and Action Planning (RAAAP) process assisted the development of multi-sectoral National Plans of Action on vulnerable children (NPAs) in 16 Sub-Saharan African countries.

Government responses

The SA government's response to the HIV and AIDS epidemic needs to be assessed and monitored against an ambitious but achievable HIV/AIDS and STD Strategic Plan (2000–2005) to which all role players have committed themselves.

This strategic plan was developed early in 2000 and it stated that all stakeholders would use this document for planning their various activities. The strategic plan is designed not only for the health sector, but rather to guide the country's response as a whole. It is meant as a framework, and it was envisaged that it would be used as a basis for the development of strategic and operational plans for government departments and other organizations. The primary goals of the plan are to:

• Reduce the number of new HIV infections (especially among young people).

• Reduce the impact of HIV on individuals, families and communities.

Its objectives are described as follows:

• Establish and implement integrated community-based care and support programmes for children infected and affected by HIV.

• Improve access to Voluntary Counselling and Testing (VCT) services for 12.5% of the population aged 15–49 years, over three years, focusing on young people and rural communities.

• Implement the life skills and HIV/AIDS education programme in 20% of primary and secondary schools in the first year, a further 40% the next year, and 40% in year three, ensuring 100% coverage by 2002/03.

• Mobilize communities through community-based HIV awareness programmes.

Following form this, the National Integrated Plan (NIP) for children infected and affected by HIV/AIDS was developed in 2002. The Government's mitigation attempts for children are being led by the NIP and this in turn is guided by the broader HIV/AIDS and STD Strategic Plan for South Africa 2000–2005. The aim of the NIP is to ensure access to an appropriate and effective integrated system of prevention, care, and support services for children infected and affected by HIV/AIDS. The NIP combines the efforts of three key government departments, Education, Health and Social Development, and focuses their efforts on expanding access to the following key programmes areas:

• Life skills education
• Home/community-based care and support
• Voluntary counselling and testing (VCT)
• Poverty relief.

The priority areas outlined in the NIP described above are propagated by the RSA government, through tools such as the Children's Act of 2005, in conjunction with other measures that attempt to counter some of the issues faced by HIV/AIDS OVCs. These initiatives are inclusive of social grants, education policies, health policies etcetera, which are related to children in general and HIV/AIDS OVCs in particular.

Even though these measures have been set out, the crisis of children living in communities affected by HIV/AIDS is largely invisible to the government because children are dispersed in families and communities where their hardships, and those who care for them, are mainly hidden from sight. As a result, government action has been slow to emerge, partly because families and communities have shouldered most of the burden and therefore 'concealing' the problem further.

The gap in government responses to this issue emerges through the fact that they are usually mirrored on international responses to HIV/AIDS OVCs. What this response thinking fails to acknowledge is the differing circumstances between different regions, states and even specific communities. So for instance, an internationally agreed upon prescriptive solution to dealing with the problem of HIV/AIDS OVCs that is developed by the United Nations may fail to recognise the particular and specific circumstances that exist for different groups of these affected children around the world.

Furthermore, government on its own does not have the capacity or the reach to successfully counter this problem on its own. Even with the Children's Act being as progressive as it is described, there still remain loopholes with regard to ensuring that the increasing problem of HIV/AIDS OVCs is adequately dealt with. While the government is responsible for assessing the extent of the HIV/AIDS OVC problem and proposing solutions, the actual implementation of these response solutions becomes that shared responsibility of government (through its various, relevant departments) and all other related non-governmental/civil society organisations.

6.2 NGO's and Civil Society Organisations

In the absence of an effective government response, NGOs drove the campaign for access to treatment, lower ART drug prices, improved care and more effective policy on HIV/AIDS. Both local and international NGOs have played a major role in assisting and protecting children, particularly those orphaned by HIV/AIDS. They do this by providing food, school fees, shelter, clothing, basic training, income-generating schemes and counselling. Many of these NGOs and civil society organisations are mandated to coordinate HIV activities, to promote common standards for implementation, monitoring and evaluation, and to strengthen delivery effectiveness. Africa Unite and many of its supporting partners are some such NGO's. Almost all the local NGOs largely depend on external donor support or on government grants for their operational costs. Huge sums have been channelled to NGOs by donors but it has often been difficult for smaller organisations to access funds. This raises questions of sustainability. Further to this, some donors have tended to push for particular responses, such as orphanages or high-profile prevention campaigns, instead of responding to local needs or priorities.

An NGOs such as Africa Unite conducts several projects that facilitate HIV/AIDS counselling, income generating activities, day-care centres and school fee sponsorship (among other things) for HIV/AIDS OVCs. They effectively volunteer to identify needy orphans, link them with foster families, serve as foster parents, monitor school fee payments, and engage in income and food generating activities. To qualify for support, the child should have lost one or both parents, be under 18 and live with a relative. In addition to the work done by AU, there are estimated to be over 150 national and international organizations providing support and care for children and orphans. However, these organizations need better coordination, integration, financial support and monitoring in order to reduce duplication. This in effect is where the gap in the NGO response to HIV/AIDS OVCs exists. NGO Services initially tended to be fragmented but in recent years, they have come together in coalitions to promote a more coherent response, directories of AIDS service organisations have been developed and information on funding for HIV and AIDS work has been collated.

6.3. Affected Communities

In many AIDS affected communities, the mechanism that keeps families and households from destitution is comprised of material relief, labour, and emotional support provided by community members. At times of distress such as bereavement, all community members are obliged to participate and contribute towards funeral costs and arrangements. People living in communities overburdened by AIDS recognise this principle, with some volunteering their time and skills to care for orphaned children. The wider community of Gugulethu where the AU, OVC project operates is one such community. In this and other similar community the extended family remains the predominant unit of care for orphans in communities with severe HIV/AIDS epidemics. Extended families involve a large network of connections among people extending through varying degrees of relationship including multiple generations, over a wide geographic area and involving reciprocal obligations.

Coping mechanisms regarding orphans are complex and vary according to social setting. In most African communities, the concept of "adoption" does not exist in the western sense. Children are fostered through a prevalent, culturally sanctioned procedure whereby natal parents allow their children to be reared by adults other than the biological parent. Child

fostering is a reciprocal arrangement and contributes to mutually recognised benefits for both natal and fostering families.

In societies where "purposive" fostering is prevalent, "crisis" fostering which occurs following the death of a parent is common. The same relatives who have a right to claim a child through purposive fostering have an obligation at times of crisis to accept the role of foster parent. Fostering by non-relatives is uncommon; the prevalence of, reasons for and hindrances to such fostering has received limited study.

The role of the extended family and community in coping with orphans are in a state of flux. Where traditional values are maintained such as in rural communities and the urban poor, the extended family safety net is better preserved. Where communities are more urbanised, extended family safety nets are weakened. As the traditional practice of orphan inheritance by uncles and aunts has lessened, it has been replaced by alternate safety nets with care provided by grandparents or other relatives. Children who slip through the safety net may end up in a variety of vulnerable situations such as street and working children and child-headed households. Monitoring the background of such children can be a valuable source of information about families which have the greatest difficulty caring for children and where efforts to strengthen capacity should be targeted.

Too often, the realisation that extended families are under stress leads to an assumption that the principal response should be to develop other alternatives such as institutions, children's villages and adoptive placements. Institutional responses are often unsustainable and may be viewed as inappropriate by members of the affected communities who recognise their potential to undermine existing coping mechanisms. The gap that needs to be filled in this instance is to ensure that those planning interventions must understand existing norms and practices in the affected communities. Responses and interventions must seek to strengthen family and community capacities to protect and care for vulnerable children. Holistic support needs to be given to these communities, above and beyond the assistance they already receive from the various sources. This support should be designed to meet their needs for housing, water, sanitation, income/job security, education, health etc. These are all important aspects to ensure the wellbeing and to improve the chances of the proper growth and development of the OVCs.

What emerges clearly from the discussion above is that the responses to the problems encountered by HIV/AIDS OVCs have been largely insufficient in dealing with the issue effectively. The HIV/AIDS epidemic and the resulting high numbers of HIV/AIDS OVCs have led to an increasing strain on the affected communities in general and the extended /"foster" families in particular. The community in the AU case study is no exception to this strain. These gaps in the responses to HIV/AIDS OVCs are what where highlighted in the nine themed experiences singled out in the case study. Evidently the OVCs concerns and priorities have not been addressed adequately.

7. Chapter Seven – Recommendations & Conclusion

The issues raised in this study are in line with those identified in the literature review. Children whose lives are affected by HIV/AIDS through the death of their parents suffer the consequences at emotional and economic levels. An exploration of their experience indicated that they feel that there has not been an adequate response to their plight. The OVCs recognise the continual efforts of government departments, NGOs, extended family structures and their communities in their efforts to address some of the hardships they experience in their day to day life.

Previous studies have focused on the socioeconomic impact of HIV/AIDS on children, and there is evidence to suggest that efforts have been made to begin to address the immediate basic needs of a number of OVCs in South Africa. Economic and other over arching circumstances in South Africa have continued to affect people's ability to perform the obligations that have long been a part of the culture of caring for family, and so fewer OVCs will find stable homes among their extended families. Due to this, the efforts of organisations such as the one selected for in the case study may have to double their efforts to contain the growing numbers of OVCs.

On an emotional level, children have been affected in several ways; primary among these is feelings of isolation, abandonment, hurt and pain. Forced entry into an adult world for which they are ill equipped has also had a significant impact.

A number of aid, non-governmental, and faith-based organisations, have performed extensive studies to try to understand the needs of OVCs. This research is done in an effort to try and respond appropriately and effectively to these needs once identified. In general however the literature does not provide evidence of the amount of work done as a result of their findings. Perhaps because of the overwhelming number of OVCs, the task of providing assistance will, for some time, continue to be focused on basic needs. However as shown in this study, emotional needs cannot be left unattended, as they can have adverse long-term effects on children's behaviour, and therefore their well being.

7.1 Recommendations to "Fill the Gaps"

It is important to note that there are concerted efforts to address the problem of HIV/AIDS' OVCs at the national level. These efforts take their cue from international level responses to the issue and then roll them out at the local/community level. The overarching initiative to address this and other development issues is the governments National Strategic Plan (NSP). While this document is comprehensive in pointing out various areas and aspects that require development attention, it clearly leaves out many of the peripheral issues that exacerbate the extent of the pandemic (i.e. poor support systems for families supporting HIV/AIDS OVCs). A lot more certainly needs to be done in terms of making the appropriate specific policies to address these issues. There is the need for social protection projects in vulnerable communities that promote and provide training for food security and nutrition support; access to social grants; income generation through micro-enterprises and community cooperatives; and community micro-financing schemes. These are some broad recommendations that should be at the core of cementing the support that is required by the HIV/AIDS OVCs. Some other broad recommendations include the following;

- Strengthen the capacity of families to protect and care for OVCs by prolonging the lives of parents and providing economic, psychosocial and other support;

- Mobilise and support community-based responses;

- Ensure access for OVCs to essential services, including education, health care, birth registration, and others;

- Ensure that governments protect the most vulnerable children through improved policy and legislation, and channelling resources to families and communities;

- Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children and families affected by HIV/AIDS.

These and other such efforts need to be strengthened and supported by all stakeholders in this issue (while these recommendations are general, they do also specifically apply to the study case of the Gugulethu OVCs). More specifically, the international community, national and local government and the affected communities should;

Build Resilience: Responses to HIV/AIDS-related issues should be holistic, covering all aspects of prevention, treatment, and care, and strive to meet the rights of all children. These responses should lie along a 'response-continuum', and range from government interventions to the support of informal networks. Responses should also take into account the need to link into and learn from other HIV/AIDS and child protection programmes, and ensure that they address a wide range of vulnerable children.

Engage all Stakeholders and the Children: Efforts to support children are best directed at the care networks and other influences that surround them. The role of government, communities, civil society, families, and the private sector is vital to ensuring a comprehensive and holistic approach to the challenge of HIV/AIDS. It is vital that children are consulted and participate in all decisions addressing them. Accordingly, interventions need to target all stakeholders to ensure that they address, in a pro-active manner, the issue of children living in communities affected by HIV/AIDS. This would provide specific frameworks of policy and forms of intervention in the nine areas/themes identified. The actual implementation of policies would be informed by the specific conditions in particular areas. The identification of the choices to be made with regard to implementation would occur through the engagement of local communities and OVCs.

Analysis-Based Strategic Interventions: Programs should be based on an in-depth analyses of the situation, these interventions should be strategic, and most important, do no harm. It is imperative that stakeholders are guided by a strong rights-based approach and coordinate their responses.

Focus on Care Givers: All children need to be in a stable and caring relationship with adult caregivers. In this regard, family-based care initiatives should be supported and monitored while avoiding, as much as possible, residential and institutional care for children. Responses

should focus on mitigating parental death and should enable caregivers to secure economic and social resources to provide for children's protection and care

Some of the proposed ways to achieve the recommendations listed above are firstly, supporting families and community-based initiatives and getting additional resources to affected households and communities on the ground. Secondly, stressing the importance of family care, as opposed to institutional care, for children without parental support cannot be understated. Thirdly, there needs to be a concerted effort towards rights-based approaches and the important role of free or at least easier facilitated access to education and health care. Fourth, there should be deliberate policy introduced to ensure social protection. One way to do this would be through the economic strengthening of affected households and growing support for cash transfers in the form of pensions and grants as a mechanism for addressing the combined impacts of HIV/AIDS and poverty. Fifth, there is a critical need for monitoring and evaluation structures and systems to ensure that the most promising models and responses are extended and scarce funds are not spent on interventions with limited impact.

In order to achieve further reductions in HIV infection and to counter the incidence of HIV/AIDS OVCs, interventions and responses to HIV with a child-specific component should be included on the national agenda – with an adequate budget commitment. The current move to strengthen capacity and coordination for protection of children at national and district level should be enhanced. Strengthening of the district response through relevant strategies and other response initiatives should be encouraged.

Behavioural change remains the mainstay of HIV control and therefore innovative strategies need to be put in place to influence such changes. A holistic approach should be encouraged if long-term behavioural change is to be realized in all groups of the population. As there is no AIDS cure yet, much more emphasis should be put on a broad spectrum of prevention programmes, especially those targeting high-risk groups. These include a 100 per cent condom distribution policy to all vulnerable groups, and the involvement of people living with HIV, students' organizations and children's groups, such as scouts and guides. This in itself helps to demystify and de-stigmatise HIV/AIDS OVCs so that the affected children can feel free to articulate their concerns so that an adequate response can be formulated.

By the same token, child-specific data and information for specific groups of the population should be collected so that a management information system can be developed. This will help in designing specific interventions, not only for HIV/AIDS OVCs, but also for other vulnerable groups. The information for the specific groups should also be linked to knowledge, attitudes, beliefs and practices regarding HIV/AIDS, so as to establish the factors that influence prevalence trends and also to plot the life experiences of individuals in these groups (in light of the response remedies).

Unclear laws/policies on HIV/AIDS and its effect on various groups leave the population at risk, particularly vulnerable groups such as children and women. It should be noted that the existing laws focusing on children have not been effectively implemented and some need to be amended.

Despite the contributions by the government, NGOs and donor community towards the control and treatment of HIV/AIDS, South Africa still faces limitations in resources to combat the pandemic. Efforts must be intensified to mobilize resources from both within and outside the country. This should also include efforts to foster regional groups (such as the Southern African Development Community), to increase the availability of interventions, including access to anti retroviral treatments and condoms, through economies of scale. By encouraging regional groupings, there can be sharing of experience among the members and scaling-up of successful practices.

When designing programmes to respond to HIV/AIDS OVCs, line ministries and agencies could consider convening a working party composed of multi-disciplinary professionals, with a critical mass of child development psychologists, in order to (accurately) address policy gaps. Further to this, there is a need to carry out further research on the effectiveness of existing intervention programmes.

The Government of South Africa, NGOs, community and civil society organisations, and the donor community should put more benefits in place for orphans, including those orphaned by HIV/AIDS, as a way of addressing such problems as street children. The response to HIV/AIDS will continue to require strong partnership and commitment on the part of the

government, the business sector, NGOs, the donors and civil society, including the general population. Only a joint effort in the response to HIV/AIDS will help reduce the impact of the epidemic on children and the general population.

The relevant government departments, civil society organisations, affected communities and other stakeholders need to recognise the fact that "it is important to listen to the voices of the children, respond to their concerns, and involve them in decisions that affect their lives. Children are the experts in their own lives and often bring valuable ideas, information and view points that adults may overlook. When children are included in decision-making, they feel a greater sense of ownership and are less fearful about what the future holds. The most effective programmes recognise the right of children to participate in ways appropriate to their age and maturity . . . organisations [can] foster participation by including youth in leadership roles, providing ways for children to share their observations and opinions, and being responsive to the needs expressed by that children themselves" (Olson, 2008:15).

7.2 Conclusions

This paper has reviewed the various responses to moderate the impact of HIV/AIDS on children. There has also been a discussion on some of the limitations of or "gaps" in these responses. The main constraint to the measures introduced so far is their nearly exclusive focus on the prevention of the disease and some other aspects of the health sector. While this kind of thinking towards a response was understandable in the early phases of the epidemic, its ability to protect and ensure child well being now appears limited. The other issue identified in this document is the heavy reliance by government on communities for the care of HIV/AIDS OVCs. This is done without the provision of adequate support structures for these communities. This demonstrates an inability by the government to think through the broad ranging implications of HIV/AIDS. Furthermore the absence of the voices of the HIV/AIDS OVCs in the processes of programme/project/policy design has led to inappropriate and ineffective action being taken.

The importance of considering the situation of HIV/AIDS OVCs has been made clear both by projections of the number of orphans expected, and the lack of adequate caring mechanisms and service structures to support them. Children and young people can be powerful agents of change when it comes to articulating their "situation" described above. When young people

are given the opportunity to express their views and participate in a meaningful way in HIV/AIDS prevention, care and support programmes, their confidence and self esteem grow. They learn important communication, negotiation and practical skills and assume civic responsibility. They become informed citizens with the power to make a real difference in their communities. Communities also benefit when young people are involved in programme design and implementation in other ways. Their unique perspective, invaluable information and insight can help to ensure that projects are relevant, effective and long lasting.

To ensure that young people are informed and effective participants, they need long term support and guidance particularly when addressing sensitive issues concerning the spread of HIV/AIDS. When young people understand the impact and implications of their efforts in the community, they can be more effective in building awareness and tolerance.

In this way, the prevention, treatment and mitigation of HIV and its effects on children can succeed if there is political commitment from the highest to the lowest levels of government. The effects of HIV on children are long lasting and profound. There is need to provide further educational opportunities to vulnerable children at primary, secondary, vocational and tertiary levels of education so as to enable them to attain some degree of economic independence. The involvement of local and international NGOs, the affected communities and the HIV/AIDS OVCs themselves in all areas of service-delivery and policymaking helps to bring all key stakeholders on board and achieves wider coverage. Communities and individual families also need to be involved in the control, treatment and mitigation of the consequences of HIV. Although these are very good lessons for other countries, South Africa still has large gaps that need to be addressed if the current momentum is to be kept on track.

A critical challenge with regard to maintaining momentum is the identification of what is "best practice to ensure the well being and proper development" of HIV/AIDS OVCs. Several approaches have been attempted with varying success in different local circumstances. However, what works well in one setting may not work as well when replicated in other settings.

The aim of this document was not to make wild claims and conclusions about the inadequacies of responses to HIV/AIDS OVCs. This discussion provides a starting point for

the construction of interventions, and for the development of further research to adequately understand the position of HIV/AIDS OVCs. The aim was to use the Africa Unite OVC Project case study to demonstrate these inadequacies with a view that doing so would allow for an investigation into the reasons for this. Furthermore, the specific research design was selected to highlight the need to have more work done using the plethora of case studies available to improve knowledge in the field of practice. Above all the lesson to take from this study is that the specific articulated experiences of OVCs in specific locations needs to be prioritised and considered in the tailor-made responses that should ultimately result. There is no one size fits all. Different communities, depending on their specific needs and prevailing national and local contexts, may require or call for a set of specific responses. There is no widely accepted model of response, but principles and strategies are agreed upon. These must evolve further to better define the vulnerabilities of affected children within communities and the meanings of rights-based approaches through their application in different contexts.

The programme and policy challenges highlighted here are only some of the difficulties facing those tasked with designing or facilitating responses to the issues faced by HIV/AIDS OVCs. The synergy needed between community-rooted responses and international and national political will is slowly emerging but is still fundamentally absent. The rhetoric of the UN led international declarations of commitments on HIV/AIDS OVCs is not matched by efforts to make such proclamations a reality. Meanwhile, on the ground, responses to the epidemic continue to evolve, mostly hidden from the eyes and ears of researchers.

Finally, addressing the psychosocial welfare elements of HIV/AIDS OVCs in affected communities is now a matter of urgency. This is put best by Cornia, who says, "The cycle of infection will be exacerbated if young people grow up in environments where mental ill health is rife, combined with feelings of isolation, despair and social disenfranchisement [all of which are described in the nine identified themes of this paper]. The responses required are in themselves not complex, but are needed on such an unprecedented scale that we are only starting to comprehend the implications" (Cornia, 2007: 337-8).

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9. Appendices

Appendix A – Biographic Questionnaire Sheet

The following information was obtained from each participant.

1. Identification number (to be assigned by Researcher).

_____

2. Date of birth _____/ _____/_____

3. Are your parents still alive?

(If the answer to this is no, then skip to No. 4)

Yes _____ No_____

4. When did your parent (s) pass away?

Year: _____

5. How old were you when your parents (s) passed away?

Age: _____

6. How many brothers and sisters do you have?

Brothers: _____

Sisters: _____

7. Are you and your brothers and sisters living together?

Yes _____ No_____

8. If not, where are they and who looks after them?

_____

_____

_____

9. When did you start participating in the AU OVC Project?

_____

10. Where and who did you live with after your parent(s) passed away?

_____

_____

_____

_____

11. Are you still in school? If not when / why did you stop, and in what grade?

Yes _____ No_____

Year: _____

_____

_____

_____

Appendix B – Sample Consent Forms / Information sheet
INFORMED CONSENT SHEET

Dear Parent / Guardian,

My name is Mesele Seyuba and I am a student at the University of Cape Town (UCT) where I am currently pursuing a master's degree in Development Studies. As part of the academic program, I am required to conduct research and compile a dissertation detailing the findings of this research. I would like to gain insight into the lived experiences of HIV/AIDS Orphans and vulnerable children. I would like permission from you as the parent/guardian, to include your child in this study.

The child will be required to complete a form with the assistance of the researcher, which will request biographic information about the child and who is caring for him/her. He/she will also be requested to take part in a group session with other children to discuss their experiences. These sessions will be audio taped and hence your permission to do this is also required.

Participation is voluntary and no child will be forced to participate. Furthermore the child may withdraw from the study at any time. All personal information obtained will be kept confidential and be used only for the purposes of this study. The research data will be destroyed after it has been analysed.

It is envisaged that the results of this study may further advance the understanding of the experiences of children affected by HIV/AIDS. It is also hoped that those involved in providing assistance and initiating support programmes for vulnerable children may be informed by the study's results.

Thank-you
Mesele Seyuba   **Date:**

OVC PARTICIPANT INFORMATION SHEET

Dear _____,

My name is Mesele Seyuba, and I am here to find out about you and children like yourselves who have been orphaned. I am currently studying at the University of Cape Town. I would like to talk to you about how you live, what you have gone through and how your lives have changed since your parents / guardians became sick and then passed away. The process will involve you and some of your friends talking and answering some questions that will be put to you. I will be present during these discussions, and the discussions will be tape-recorded.

I will need your permission, in writing on the form provided, if you wish to take part in the discussions. I will also need your permission to use a tape recorder.

I am hoping that the information you give me may help those who read my report to understand the experiences of children such as yourselves. It is also my wish that people involved in providing assistance and initiating support programmes for orphans and vulnerable children may find the information useful.

You do not have to take part, if you do not want to. Also you can withdraw from the study at any time should you choose to attend in the first place. I will make sure that all the information that you give me about yourselves is kept anonymous and will be used only for the purposes of this study. Since you will be having a discussion with your friends from the Africa Unite OVC project, it is important that you agree to keep to yourself what is discussed between the people at these discussions and not to talk about it outside of the group taking part. If you start to feel uncomfortable or sad during the process, there will be someone here to help you.

Please feel free to ask any questions if you are not clear on any part of this letter.

Thank-you

Mesele Seyuba   **Date:**

PARTICIPANT CONSENT FORM

LEGAL GUARDIAN

I have read and understand the information provided above about the study and the process involved. I, being the parent / legal guardian, hereby give my consent for the child named below to be included in the study. I understand that the child will also be given the choice as to whether to take part in the study or not.

Name and Signature: **Date:**

(Parent/ legal guardian)

Name of child _____

Mesele Seyuba   **Date:**

Appendix C – Focus Group Interview Schedule / Outline

Questions for the focus group discussions

1. Please tell us about the changes that have occurred in your life since your parent (mother, father) became ill or passed away.

 • What daily activities in your life have changed and how?

 • How long ago did your parents pass away and how has your life been, in general, since then? Talk about your experiences.

2. For those of you that have lost a parent(s), could you please talk about how this has made you feel?

 • How did you feel when you saw your parents getting sicker?

 • Were you involved in caring for your parents when they were ill? What did you do?

 • What was the experience of caring like for you? How did you cope with these new responsibilities?

3. What do you remember / miss most about having your parents and living together as a family?

 • Is there anything that you don't miss or is it better now?

 • What do you remember about your parents?

 • Do you have anything to remind you about them? What is it and how does it make you feel when you see it?

4. Please talk about how you have managed to survive without your parents to look after you.

 • What have you done, or what could you do to make yourself feel better?

 • What sorts of things do you do when you feel sad and lonely?

 • How have other people helped you to deal with the feelings that you experience?

5. Please talk about the help you receive

 • Who do you receive help from and what kind of help do they give?

 • What do the government and your community do to help you?

 • What does Africa Unite do for you to make your life better/easier?

- Exactly what kind of help do you most want to receive form government, Africa Unite and you community?

6. What do you think would make your better now?
• Do you have plans for the future?
• What would you like to see happen in your life now?

Appendix D – Graphs Indicating HIV/AIDS Prevalence in Sub Saharan Africa.

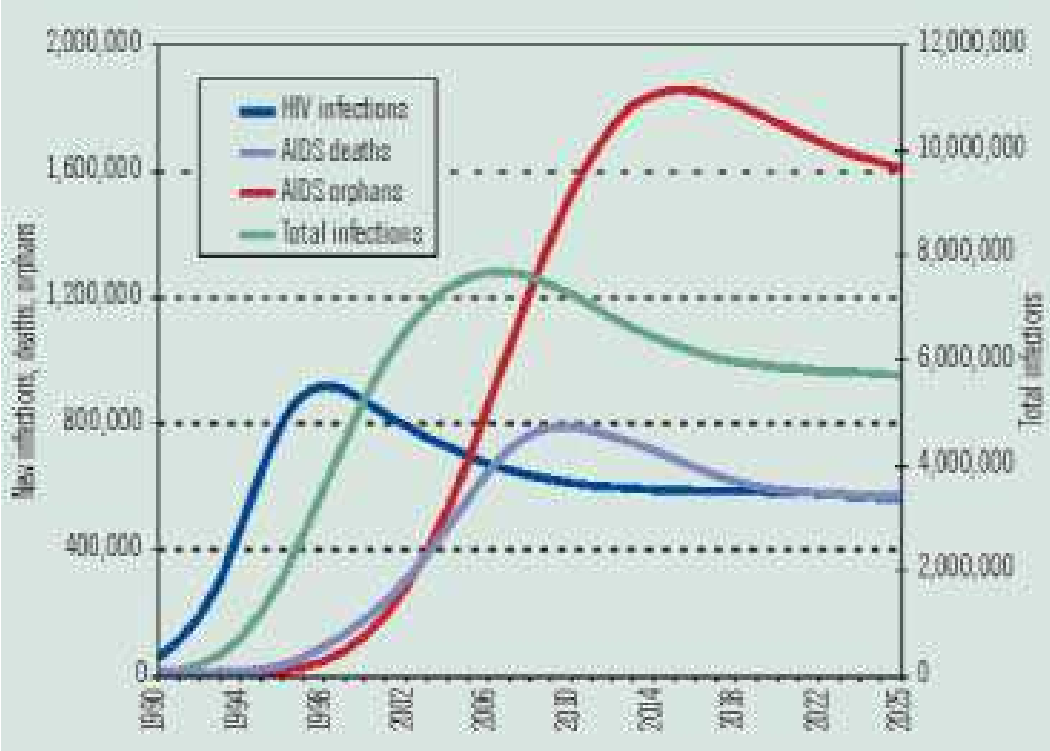Figure 1. Waves of the Aids Epidemic (UNICEF & UNAIDS, 2006)

Figure 2. Numbers of AIDS Orphans and non AIDS Orphans Compared (UNICEF & UNAIDS, 2006)