

https://dspace.org/

Reconceptualising 'care' for vulnerable children in the context of HIV/AIDS : a case study of Cotlands.

Guvava, Dorothy Dorica

2012-02-10
http://hdl.handle.net/10539/11272

Downloaded from a DSpace repository. https://dspace.org/

RECONCEPTUALISING 'CARE'FOR VULNERABLE CHILDREN IN THE CONTEXT OF HIV/AIDS: A CASE STUDY OF COTLANDS

By

DOROTHY DORICA GUVAVA

A thesis submitted in partial fulfilment of the requirements for the degree of

Master of Arts in Health Sociology

UNIVERSITY OF THE WITWATERSRAND

2011

Supervisors: Louise Hagemeier and Kezia Lewins

Declaration

I, Dorothy Dorica Guvava (Student No. 0107352K), hereby declare that this research report is my own unaided work. It is submitted for the degree of Master of Arts in Health Sociology at the University of the Witwatersrand, Johannesburg. It has not been submitted or presented for any degree or examination at this or any other university.

Signed at Johannesburg on the……..day of October 2011.

Dorothy Guvava
Student Number : 0107352K
Department of Sociology
School of Social Sciences
University of the Witwatersrand, Johannesburg

TABLE OF CONTENTS **PAGE NUMBER**

ACKNOWLEDGEMENTS vi
ACRONYMS vii

CHAPTER 1: INTRODUCTION **1**

1.1 Research Aims and Objectives 3

1.2 Research Question and Sub-questions 4

1.3 Rationale of the Study 6

CHAPTER 2: LITERATURE REVIEW **9**

2.1 Introduction 9

2.2 The HIV/AIDS Epidemic 9

2.2.1 Dimensions of the HIV/AIDS Epidemic 10

2.2.2 Characteristics of HIV/AIDS 11

2.3 The Impact of HIV/AIDS on Children and on their Development 13

2.4 Vulnerability of Children in the Context of HIV/AIDS 15

2.5 Needs of Vulnerable Children in the Context of HIV/AIDS 16

2.5.1 Needs of Vulnerable Children Identified in Recent Studies 17

2.5. 2 Social Context in which Many **HIV/AIDS** Vulnerable Children are Located 19

2.6 Definition and Conceptualisation of Care 20

2.6.1 Types of Care Provided for HIV/AIDS-vulnerable Children 20

2.6.2 Changes in Care Patterns 23

2.6.3 Important Concepts of Care 34

2.7 Family Responses to Vulnerable Children 38

2.8 Government Responses to Vulnerable Children 40

2.9 NGOs Responses to Vulnerable Children 42

2.10 Conceptual Framework 44

CHAPTER 3: RESEARCH METHODOLOGY 48

3.1 Overall Approach 48

3.2 Research Methodology 48

3.2.1 Document Analysis 49

3.2.2 Semi-structured Interviews 49

3.2.3 Participant Observation 51

3.3 Method of Data Analysis 52

3.4 Ethical Issues 53

3.5 Limitations of the Study 55

CHAPTER 4: COTLANDS MODIFIES 'CARE' IN THE CONTEXT OF HIV/AIDS 57

4.1 The History and Overview of Cotlands 57

4.2 Who Needs Care in the Context of HIV/AIDS? 60

4. 3 Cotlands Redefines 'Care' in the Context HIV/AIDS 63

4.3.1 Changes to the types of care provided 64

4.3.2 Multidisciplinary team brings different expertise to Cotlands 'care' 79

4.4 Scaling up the 'Islands of Excellence': Cotlands' Forms of Care Redefined 82

4.4.1 Cotlands Institutional Care 83

4.4.2 Cotlands Community-based Care 88

4.5 Cotlands Builds Partnerships 96

CHAPTER 5: EXPLANATION AND EVALUATION OF INSTITUTIONAL CARE AND CBC 99

5.1 Scaling Up Heightens the Model of Care Debates: Institutional Versus CBC 99

5.1.1 Practicality of Cotlands Institutional Care- the 'Good' and the 'Bad' 100

5.1.2 The Practicality of Community-based Care: What is Unsaid About the Model 104

CHAPTER 6: SUSTAINABILITY AND EFFECTIVENESS OF CARE PROVIDED BY COTLANDS 115

6.1 Sustainability of Cotlands and Care Services it Provides 115

6.2 Assessing the Effectiveness of Cotlands' Care 118

6.2.1 Maintenance of Social Reproduction 118

6.2.2 Provision of Social Capital 120

CHAPTER 7: CONCLUSION AND RECOMMENDATIONS 122

7.1 Conclusion 122

7.2 Recommendations 124

REFERENCE LIST 126

Appendix 1: Essential elements for realising orphans & vulnerable children's right 135

Appendix 2: Permission letter 142

Appendix 3: Participant information sheet 144

Appendix 4: Participant consent form 146

Appendix 5: Interview schedule 147

Appendix 6- Cotlands Time-line 151

ACKNOWLEDGEMENTS

Many thanks to all Cotlands employees and managers who freely shared their knowledge and experiences. Most importantly, I would like to thank the children and other clients of Cotlands for the time I spent with them. Everyone's contribution was incredibly valuable for this study.

My heart-felt gratitude also goes to my supervisors, Louise Hagemeier and Kezia Lewins, for their patience, guidance and constructive advice.

Special thanks also go to my family, Abigail, Edias, Ethy, Miriam and especially to my daughter, Paidamoyo, for their endurance.

Many thanks to Professor Dennis Schauffer for language editing. I would also like to thank Tobias Makanda and Alex Matewa for their editorial contribution. I also want to give special thanks to my friends James Strumpher and Professor Moutlana for all their support.

ACRONYMS

AIDS- Acquired Immune Deficiency Syndrome

ART- Antiretroviral Therapy

ARV- Antiretroviral

CBC- Community-Based Care

CHBH- Chris Hani Barangwanath Hospital

CTC- Community-Based Therapeutic Care

ECD- Education Childhood Development

HBC- Home Based Care

HIV- Human Immunodeficiency Virus

OVC- Orphans and Vulnerable children

MTCT- Mother to Child Transmission

NGO- Non-Governmental Organisation

TFC- Traditional Feeding Centre

PMTCT- Prevention of Mother to Child Transmission

UNICEF- United Nations International Children's Fund

CHAPTER 1: INTRODUCTION

The death from HIV/AIDS of millions of people, some of whom are primary caregivers and breadwinners, has dramatically changed the profile of who bears the burden of caring for vulnerable children left behind and the kind of care these children receive. Families have always been a place for a child's nurturing and development. However, as the number of children rendered in need of care by HIV/AIDS overwhelms these families, NGOs have had to step in to alleviate the burden on such families and governments. Yet, little attention has been given to how care provided by these NGOs has diversified and changed so that they can deal effectively with the challenges of the disease and the needs of vulnerable children. This study intends to investigate how care has been conceptualised by a South African Non Governmental Organisation, Cotlands, in the context of HIV/AIDS. The fact that Cotlands which was founded in 1936, has always played an important role in supporting vulnerable children makes it ideal for understanding how care has changed as a result of HIV/AIDS. By comparing the past care practices (before the impact of the disease) and the present care provided, an understanding on how care has changed can be explained and assessed.

South Africa has the world's largest population of people living with HIV/AIDS (UNAIDS, 2010). Currently, 5.7 million people are infected, approximately 930 000 people are infected every year and 250 000 people die annually from the disease (AIDS Foundation South Africa, 2008; UNAIDS, 2010). At this rate, a third of all South African children are expected to be orphaned by 2015 if there are no effective interventions that bring about the necessary sexual and social behavioural changes (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002). The death of economically active people due to HIV/AIDS renders numerous people vulnerable and further increases the demand for care of vulnerable children (Mnubi-Mchombu, Mostert & Ocholla, 2009; UNICEF, 2006). Most important for this research is that the increased demand for care, challenges of the disease and the range of people made vulnerable as a consequence of HIV/AIDS, has necessitated the re-conceptualisation of care. According to Hise (2005:2), "reconceptualisation begins with what we know and provides attempts to re-think and re-imagine the processes that produce a phenomenon." In order to understand how

'care' has been re-conceptualised, the study explored the ways through which 'care' has been redefined and implemented in the context of the HIV/AIDS epidemic.

It has been argued that the epidemic has become more dynamic, complex and volatile (Mann & Tarantola, 1996; Madzingira, Mamimine, Mkaronda & Marimo, 2008). A part of this complexity is the diversity of vulnerable people now in need of care. Vulnerable people include children orphaned by the HIV/AIDS-related death of their parents, sexually abused children, poor, infected children, youth who are particularly susceptible to HIV/AIDS, and pregnant women whose unborn children maybe at risk of contracting the disease (Mnubi-Mchombu, Mostert & Ocholla, 2009;WHO Technical Report Series 898, 2000). The types of vulnerability emergingfrom the above categorisation are as follows: firstly, vulnerability as a result of their positive HIV/AIDS status; secondly, vulnerability to becoming HIV positive and developing AIDS despite currently being HIV negative; and thirdly, vulnerability as a result of an HIV/AIDS-related death or the management of the disease within the immediate family or household. These people are in serious need of assistance with the activities of daily living, in order to enjoy a reasonable quality of life (WHO Technical Report Series 898, 2000). This study mainly focuses on children.

The rise in the number of vulnerable children, especially orphans, is one of the most tragic long-term consequences of the HIV/AIDS epidemic. This has contributed to the overburdening of traditional kinship-based care mechanisms (Makape, 2008) and has a direct impact on the need for provision of care by governments and NGOs. Gordon, Benner and Noddings (1996) and Villarreal (2006) argue that care-needs have expanded to such an extent that the traditional mechanisms of care can no longer cope with the demand. Families, communities and governments can no longer bear the primary responsibility of caring for vulnerable children without the involvement of NGOs. This means that NGOs' assistance in developing mechanisms for the pooling of individual and community resources has become very important in enabling the provision of adequate care (Waerness, 1996; Rayneke-Barnard, 2005)

Whilst acknowledging that the impact of HIV/AIDS on care "can be observed at all levels of society including the individual, household, community, profitable and non-business, and unlimited to non profitable business, that is NGOs. This was studied through the case study undertaken at Cotlands. This is a South African organisation that cares for abandoned or orphaned children and children infected and affected by HIV/AIDS through the provision of both residential and community-based care (CBC).

NGOs, such as Cotlands and SOS Children's Villages , that primarily focus on caring for orphaned and destitute children, have been greatly affected by the epidemic and by the large number of people rendered vulnerable and in need of care. From the 1990s when HIV/AIDS started taking its toll on the nation and families, these NGOs have had to redefine 'care' in the context of the disease and have thus had to re-evaluate and modify their traditional provision of care. If these organisations do not continuously change to accommodate the challenges of the epidemic, they would run the risk of becoming irrelevant and ineffective (Maritz, 2002; Villarreal, 2006). Changes to the conceptualisation of care can be seen through the responses of organisations to the epidemic, such as the introduction of initiatives, policies, programmes and models that are directed at effectively caring for infected and affected persons (Boon, Ruiter, James, Van Den Borne, Williams & Reddy, 2009). This study investigated how Cotlands defines care in the context of HIV/AIDS, what models of care it currently uses, and how its care mechanisms and initiatives have changed over time due to HIV/AIDS.

1.1 RESEARCH AIMS AND OBJECTIVES

The main aim of this research was to investigate how care is re-conceptualised by a non-governmental organisation (Cotlands) in South Africa, in the context of HIV/AIDS. To this end, the objectives of this research were:

1. Briefly to explain the background characteristics and dimensions of HIV/AIDS in order to understand the challenge confronting NGOs.

2. To explain the impact of HIV/AIDS on children's development in order to better understand what kind of care is needed to ensure vulnerable children develop into socially and economically active adults.

3. To identify the needs of children rendered vulnerable by the disease and the types of care that can address these needs.

4. To investigate the impact of HIV/AIDS on the care provided en in South Africa.

5. To describe and explain how 'care' has been redefined and applied in the context of HIV/AIDS. This is done by exploring Cotlands' policies, goals, objectives, mission, caring initiatives/programmes and models targeted at meeting the needs of children made vulnerable by HIV/AIDS.

6. To investigate how these care objectives, programmes and models are aligned to: the characteristics of the epidemic; the challenges of the disease; and to the needs of the vulnerable children.

7. To explore and describe the perceptions of Cotlands' employees regarding the effectiveness of Cotlands' care mechanisms, with specific reference to its ability to meet the needs of its beneficiaries.

8. To provide recommendations on how 're-conceptualised care' can effectively be implemented to address the needs of vulnerable children and adults in the HIV/AIDS context.

1.2 RESEARCH QUESTION AND SUB-QUESTIONS

The research question for this study was:
How is 'care' for vulnerable children re-conceptualised by a South African non- governmental organisation, Cotlands, in the context of HIV/AIDS?

To answer this question the following issues and sub-questions were addressed:

Firstly, through a literature review, the broad context of HIV/AIDS including its characteristics and dimensions were explored. In addition, the impact the disease has on the lives and development of children was examined. This included identifying the needs of children rendered vulnerable by the disease. Reference to these issues was essential to understand the unique characteristics and challenges of the epidemic and thus to provide the basis for exploring and explaining why there is a need to re-conceptualise 'care' in the context of the disease.

Secondly, it was important to examine how 'care' was defined and applied in the absence of the disease, and how this has changed or has been modified so as to accommodate the challenges presented by the epidemic. In order to do so, this research explored the traditional mechanisms of care and how HIV/AIDS has impacted on these. The exploration of this was important to be able to explain the need for NGO involvement. It also explored how Cotlands cared for its beneficiaries in the absence of the disease. The following sub-questions were used to investigate how care has changed and has been re-conceptualised by Cotlands.

1. What are the debates around the models of care for vulnerable people? How have models of care changed as a result of HIV/AIDS?
2. How is 'vulnerability' as a result of HIV/AIDS defined?
3. How do the needs of HIV-positive children differ from those who are negative?
4. How does caring for children with HIV/AIDS differ from caring for those who are HIV negative?
5. How has the role of care-giving changed as a result of HIV/AIDS?
6. Have there been any changes in staff recruitment and requirements for care-giving?

Finally, the intention was to evaluate the effectiveness of the 'care' that is provided by Cotlands. This included evaluating the extent to which Cotlands' programmes and initiatives address the characteristics, consequence and challenges as a result of the epidemic.

1.3 RATIONALE OF THE STUDY

The rampant spread of HIV/AIDS renders millions of children vulnerable to the disease and has overwhelmed traditional care mechanisms such as the use of the extended family (Villarreal, 2006; Makape, 2008). As a result, re-conceptualization of care is important for providing an understanding of the diversity and the changing nature of 'care' that can effectively meet the needs of these children in the context of HIV/AIDS. In so doing, this study adds to the body of knowledge, debates and effective approaches to caring for people, especially children, made vulnerable by the epidemic. Therefore this study is important for caregivers and organisations which provide care for vulnerable people aiding their policy formulation and strategic planning.

Whilst studies have focused on the care provided by the health sector in the context of HIV/AIDS, very little attention has been given to other sectors such as NGOs, whose primary function is to care for vulnerable people (Villarreal, 2006). This research addressed this gap by using Cotlands to explore how this particular NGO has re-conceptualised 'care' in the context of the HIV/AIDS epidemic.

The fact that Cotlands was established before the discovery of HIV/AIDS provided a platform from which the researcher was be able to explore the nature of 'care' and care-giving activities in the absence of the epidemic. Hence, to some extent, the researcher was able to compare the past and the present knowledge of care practices so as to gain an understanding of how the organisation has re-conceptualised 'care' in the new context.

There two main models of care which are utilised in South Africa to care for vulnerable children which are the institutional model and the Community-based care (CBC) model. Institutional or residential care is "a group living arrangement for children in which care is provided by remunerated adults" (Rayneke-Barnard, 2005: 23). community-based care is "care that the individual can access nearest to home, which encourages participation by the people in the communities." (Ncama, 2005: 33). Existing literature and research has documented the importance of community-based care (CBC) in meeting the needs of children made vulnerable by HIV/AIDS (Tolfree, 2003; Loening-Voysey & Wilson, 2001; Phiri & Webb, 2002).In most

cases researchers have done so by citing the negative effects of institutional care, which include its inability to meet the psychosocial needs of children and most importantly its inability to accommodate the massive number of children in need of care. In the process, community-based care has been cited as the most effective model of care. However, those who cite it as most effective have "a greater assumption that communities are homogenous and unproblematic entities" (Russel & Schneider, 2000: 328). There is a tendency to over-simplify the concept of community-based care whilst down-playing its practical challenges. By doing so, little thought is given to the challenges and barriers that may hinder vulnerable children in communities from benefiting from care services that may be provided by NGOs. As a result, the aim of this study is to examine how institutional and community-based care models are implemented and how they work in practice by focusing on Cotlands.

This research hopefully provides implementers of care, policy makers, regional and international organisations with recommendations on how to redefine care, and on how to implement effective care programmes or initiatives that would be capable of meeting the needs of vulnerable persons in the context of HIV/AIDS.

This report is structured in the following way: Chapter two presents the literature review and the theoretical framework of the study. A review on challenges of HIV/AIDS, the needs of vulnerable children, types and theories on care and the impact of HIV/AIDS on families and the families' responses in terms of provision of care is provided. In addition, the responses by NGOs (that care for vulnerable children) in terms of assisting families and children are provided. This review of relevant studies provided the platform against which the findings of this study are explained and benchmarked. In addition, a conceptual framework of key operational definitions is presented.

Chapter three presents the methodology of the study. It begins by explaining the extended case study method and presents the rationale for its use in this study. Research methods and methods of data analysis are provided. The sample for the study is also explained. Lastly, ethical considerations and limitations of the study are presented.

Chapter four provides the history of Cotlands. Findings on the changes including the number of children in care, types of care provided to the children, staffing and staff requirement in order

to deal with the challenges of HIV/AIDS are presented. Changes in the models/means of care are identified.

Chapter five gives a full discussion, explanation and evaluation of both the institutional and community-based care provided by Cotlands. Findings on the strengths and challenges of the two models in meeting the needs of vulnerable children in the context of the disease are then provided.

Chapter six provides findings on the sustainability of care provided by Cotlands and on the effectiveness of care provided by the organisation. The effectiveness of care provided by Cotlands was assessed in terms of maintaining social reproduction and providing social capital.

Chapter seven presents the conclusion and recommendations of the study. The study concluded that, in the context of HIV/AIDS, care requires a holistic approach and the combined use of institutional and Community-based care .One of the main recommendations of this study suggests how Cotlands can improve the secondary beneficiaries' utility of services such as the income generating projects provided by the organisation.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The aim of this study was to investigate how 'care' for vulnerable children in the context of HIV/AIDS has been re-conceptualised by Cotlands. This literature review explores how care of vulnerable people has traditionally been conceptualised and makes the case for a re-conceptualisation of care, in the context of HIV/AIDS, as argued by existing literature and research.

The background to the HIV/AIDS epidemic is explored including its characteristics and dimensions. It then explores the impact of HIV/AIDS on children's development and discusses the needs of vulnerable children. This is followed by a discussion of the impact of the epidemic on the provision of care by families, communities and the response by government is explored. This background explains the need for NGOs' involvement in the provision of care and the motivation for a re-conceptualisation of 'care'. The literature review provides the basis against which the research findings can be compared. The chapter ends with the presentation of the conceptual framework and presents the working definitions of key concepts used in the study.

2.2 THE HIV/AIDS EPIDEMIC

HIV/AIDS is not the first global epidemic and will not be the last (Barnett & Whiteside, 2000). However, it has unique dimensions and characteristics which may lead to intense challenges in meeting the needs of vulnerable children (Maritz, 2002). This study investigates the extent to which Cotlands' care has been informed or influenced by various dimensions and the characteristics of the disease, firstly, how this has affected the implementation of care, and secondly, the types, nature and models of care provided by the organisation.

2.2.1 DIMENSIONS OF THE HIV/AIDS EPIDEMIC

This dimensional exploration of the epidemic illustrates the magnitude of the problem, in terms of numbers of children in need of care. This also justifies the necessity to redefine 'care' in the face of the need to cope effectively with the large numbers of vulnerable children

HIV/AIDS was diagnosed in the 1980s and more than 25 million people have since died from the disease worldwide (Avert, 2011). According to UNAIDS (2008: 4) of the "33 million people living with HIV/AIDS, two-thirds live in sub-Saharan Africa, despite this region containing only a little more than 10% of the world's population".

South Africa has the highest HIV/AIDS prevalence and also has the largest number of children orphaned and made vulnerable by this epidemic in the world (UNAIDS, 2010; Anderson & Phillips, 2006). Five million seven hundred thousand people are infected (AIDS Foundation South Africa, 2008; UNAIDS, 2010). HIV/AIDS represent nearly one sixth of the total global disease burden (UNAIDS, 2010).

Even though the death rate has recently declined, HIV/AIDS is still considered the number one killer in South Africa. Despite the introduction of the "Prevention of Mother to Child Transmission (PMTCT) programme, a substantial number of children are still born HIV positive" because of a lack of access to initial and follow up treatment (Kvalsig, Chhagan & Taylor, 2007: 40).

Freedman and Nkomo (2006: 302) asked "What will happen to Africa's orphans and other vulnerable children (OVC) in the coming decade?" Globally, South Africa has the largest number of children orphaned and made vulnerable by HIV/AIDS. USAID (2007:2) estimates "3.3 million children in South Africa have lost at least one parent to HIV/AIDS and this is expected to exceed 5 million by 2015." It is also estimated that, without any significant health, social or sexual behavioural changes, around "one third of children under the age of 18" would have lost one or both parents to the disease by 2015 (Freedman & Nkomo, 2006: 302). Questions regarding care arise. Who bears the burden of caring for the children left behind and

what kind of care do these children need? These are some of the questions that will subsequently be addressed.

2.2.2 CHARACTERISTICS OF HIV/AIDS

According to Villarreal (2006:55), in order for "government ministries, NGOs, communities, families and individuals to effectively manage HIV/AIDS", it is important that they have an understanding of the characteristics of the disease. Maritz (2002) and Haddad and Gillespie (2001) have identified the following unique characteristics:

HIV/AIDS is a non-curable and fatal epidemic: Three decades after HIV/AIDS was identified as a specific condition, no cure has yet been found. In the absence of a cure, life-long care for the vulnerable has become the norm (Jamil & Muriisa, 2004; Haddad & Gillespie, 2001).

HIV can develop into a chronic disease (AIDS): AIDS is the serious chronic condition/syndrome that develops years after infection with the HI Virus (Maritz, 2002). The central characteristic of HIV is its ability to attack the body's immune system making the body vulnerable to, otherwise rare, opportunistic infections and cancers (Maritz, 2002; Haddad & Gillespie, 2001). As a result, caring for those infected involves managing HIV so that it does not develop into AIDS. Even though the progression of HIV into AIDS varies from person to person, Antiretroviral Therapy (ART) is an essential component of care for those who are HIV positive (Haddad & Gillespie, 2001).

HIV/AIDS leads to a large number of Orphaned and Vulnerable children (OVC): As discussed above, the scale of orphans and people made vulnerable by HIV/AIDS is significant. As a result traditional care mechanisms have been overwhelmed.

HIV/AIDS is a highly stigmatized disease: HIV/AIDS is perhaps the most stigmatized medical condition in the world. Stigmatization remains a core feature of the patient experience of HIV/AIDS (Gilbert, Seliskow & Walker, 2010). The "private nature of, and the divergent cultural attitudes towards the disease lead to silence, denial, stigma and discrimination at all levels" (Haddad & Gillespie, 2001:7). This contributes to people's fear and explains their reluctance to find out their HIV status and why facilities are not fully utilised despite being accessible. Hence, care mechanisms also need to address the issue of stigma.

Risk group: According to Maritz (2002:34) the disease is found in mainly two specific age groups: infants and adults between 20 and 40 years. This study investigates what measures Cotlands has taken to assist these risk groups .

Adequate nutrition: According to Erasmus (2009:iv) "a common consequence of HIV/AIDS infection is malnutrition and weight loss, which is used as one of the diagnostic criteria for HIV/AIDS." According to Nannan, Norman, Bradshaw, Hendricks & Dhansay (2007) adequate nutrition cannot cure HIV/AIDS but it is essential to maintain the immune system, to support physical activities and to achieve optimal quality of life. It is also required to optimise the benefits of antiretroviral drugs (ARVs) and to prevent Mother to Child transmission (MTCT) (Nannan *et al*., 2007). Therefore, provision of adequate nutrition is regarded as a crucial part of caring for the vulnerable, especially those who are HIV positive.

Modes of transmission of HIV: Most HIV infection is through sexual activity, direct contact with blood, or from a mother to her unborn child (Maritz, 2002). The primary mode of transmission is through sexual activities and the second is mother–to-child-transmission (MTCT) (Maritz, 2002). As a result of this, caring for the vulnerable also has to include preventative measures such as encouraging infected pregnant mothers to take ARVs to prevent MTCT and to encourage the uninfected vulnerable parties to refrain from risky behaviour.

Identification of these characteristics enable this study to investigate how 'care' has been redefined and applied by Cotlands in accommodating the challenges of the epidemic. This allows for an assessment of the effectiveness of Cotlands' current care model and response to the HIV/AIDS challenge.

2.3 THE IMPACT OF HIV/AIDS ON CHILDREN AND ON THEIR DEVELOPMENT

HIV/AIDS has had a tremendous impact on sexually active, productive and reproductive groups (Loening-Voysey & Wilson, 2001; Villarreal, 2006). This has had a direct and indirect impact of on the lives of children in a number of ways. A large number of children are HIV positive. According to Mathambo and Richter (2007: 11) "in 2006, it was estimated that 293 549 children were living with HIV in South Africa, with 40% ...requiring antiretroviral treatment". These children are either born with the disease or are the victims of myths such as

the ‘Virgin Cure’, whereby some people believe that having sexual intercourse with a virgin would cure them of HIV/AIDS (Gilbert *et al.*, 2010). This has contributed to young children being raped and contracting HIV.

Other than some of the children contracting the disease, Phiri and Webb (2002) stated that the illness or death of a parent to HIV/AIDS also has psychological, social and economic impacts on children. Togom (2009) stated that death of a breadwinner has a serious economic impact on children. The children are likely to live in dire poverty due to the loss of the source of income. These children have had to go hungry and have problems with shelter and other material needs (Togom, 2009). Economic hardship has contributed to some children selling sexual favours so as to fend for their siblings (Phiri & Webb, 2002). This has contributed to the children getting sexual abused and exploited.

In addition, HIV/AIDS has had a social impact on children. Children have had to take up adult roles such as caring for dying parents or siblings left behind. In addition, children whose parents are sick or die of HIV/AIDS experience high levels of stigma and discrimination at school and in communities, which may lead to these children isolating themselves (Gillespie, Norma & Finley, 2005). As a result of high levels of stigma and loss of income, the children’s education is likely to be affected by the death or illness of a parent. As stated by Mathambo and Richter (2007:11) “if a parent dies, a child’s education is more likely to be interrupted than if no parent dies” and these children are likely to fall deeper into the cycle of poverty.

Death of a breadwinner/caregiver, caring for the sick, stigma and discrimination experienced by children also have a psychological impact on the children. As the children experience such trauma, they may go through anxiety, self-blame, distress, depression and stress (Togom, 2009). Literature shows that whilst emphasis is largely placed on the material impact of the disease, the psychological and social impact of the disease is largely ignored when addressing the impacts of HIV/AIDS.

Recent studies have also revealed that HIV/AIDS has a serious impact on children’s development. Development is defined as “changes in or gradual unfolding of the physical

structures and cognitive, social and psychological processes that take place within an individual and which lead the individual from one stage to another" (Goldberg, 1993: 56). Development is crucial for an individual in a society to become a contributing and, economically and socially productive adult. According to Kvalsvig *et al.* (2007: 3) a "child's early years are crucial for development: in the earliest years of childhood, survival, growth and development are interlinked; growth affects both chances of survival and the child's development, and all three are influenced by family care practices, resources and access to services." It is during the first four years of a child's life that he/she undergoes rapid physical, mental, emotional, social and moral growth and development. As stated by Engle, Young, Tacon and Yuster (2004: 5) "insufficient stimulation, nurturing and nutrition and health problems in young children due to death or illness of a caregiver can have long term consequences in the child." In this regard, one of the most traumatic impacts of HIV/AIDS pertains to child development.

In the absence of ARVs children rarely lived past the age of five (Phiri & Webb, 2002). Whilst focus by many countries and NGOs was on finding the means to ensure survival of children, little emphasis was put on ensuring their development. However, the development of ARVs has led to a reduction in mortality rate and this has enabled these children to live to adulthood. Whilst this is definitely a cause for celebration, there is a realisation that "children with HIV infections are at higher risk of neurological insult (impact), developmental delays and other lower cognitive scores than those who are uninfected" (Kvalsvig *et al.*,, 2007: vii). Some children born HIV positive begin to show retarded growth and development during the first few years of their lives (Phiri & Webb, 2002).Whilst some of the delays and neurological insults caused by the HI virus, leading to such compromised growth, may be arrested or reversed by ART, some are difficult to reverse because of the biological effects of the HI virus (Kvalsvig *et al.*, 2007). However, there is a greater acknowledgement of the fact that most of the above-mentioned biological effects of the HI virus that can hinder a child from developing into a socially productive and economic adult can be addressed though the kind of care the child receives (Kvalsvig *et al.*, 2007). The next section discusses a child's vulnerability in the context of HIV/AIDS.

2.4 VULNERABILITY OF CHILDREN IN THE CONTEXT OF HIV/AIDS

As argued by Gillespie *et al.* (2005) the concept 'vulnerability' is commonly used but often not well defined. It is a concept that has had differing meanings across and within disciplines. The multiple impacts of the disease also shape 'vulnerability' in many ways.

In the context of HIV/AIDS, some studies have defined children's vulnerability in terms of orphaning, others as deprivation and some see these as interlinked (Gillespie *et al*., 2005; Mathambo & Richter, 2007). Recent studies conceptualize vulnerability as involving both those who are affected or infected by the disease. Gillespie *et al.* (2005) provide a more comprehensive categorisation of vulnerable children encompassing the multidimensional impact of HIV & AIDS:

- "Children who have lost one or both parents to AIDS (maternal, paternal and double orphans) wherever they live, including on the street;
- Children whose parents are alive but who live with relatives or non-relatives under strained capacity (often identified as social orphans);
- Children living in households with adult caregivers (parents or non-parents) or other siblings who are chronically ill, possibly due to HIV/AIDS;
- Children who are HIV-positive or living with HIV and AIDS, some of whom may be orphans;
- Children in poor households who are not orphaned but experience an adult death; and
- Children living with their parents in fostering households, which may have recently taken in an orphaned child" (Gillespie *et al*., 2005:2)

The above categorisation recognises that vulnerability of children is as a result of multiple factors including poverty, illness/death of a caregiver or breadwinner, child-headed families and so on. Vulnerability leads to children's needs which need to be addressed through care. Therefore, before exploring the concept of 'care' it is important firstly to identify these needs.

2.5 NEEDS OF VULNERABLE CHILDREN IN THE CONTEXT OF HIV/AIDS

A number of studies have been conducted to investigate the needs of vulnerable children. Most have shown that all children have basic needs whether vulnerable or not. Hence, this section will briefly explore some of these needs based on the most influential studies.

One of the most influential studies is Max-Neef's framework of children's fundamental needs (Loening-Voysey & Wilson, 2001). He argues that "all children have physical, emotional, social, spiritual and intellectual needs that must be met if the children are to enjoy life, develop their full potential and develop into participating, contributing adults" (Max-Neef, 1991, *In* Van Dyk, 2008: 345). He also states that these needs are constant across all cultures and all times; what varies over time and between cultures is the way these needs are satisfied (Van Dyk, 2008). Whilst some needs, such as physical needs, are important for a child's survival, others, such as social, spiritual and intellectual needs, are important for a child to achieve full development and to live a productive life (Loening-Voysey & Wilson, 2001).

Drawing mainly from Max-Neef, Loening-Voysey & Wilson (2001) developed a comprehensive list that especially takes account of the needs of vulnerable children. A full list is provided in appendix 1. To summarise , the needs of orphans and vulnerable children can be divided into the following categories:

- **survival** including food, clothing, shelter and health care;
- **security** including love, affection, protection against abuse, neglect and exploitation;
- s**ocialisation** including understanding, identity, participation and access to basic psycho-social services; and
- **self-actualisation** including recreation, leisure and freedom of expression.

  (Loening-Voysey & Wilson, 2001:13).

Max-Neef (1991, *In* Van Dyk, 2008) and Loening-Voysey and Wilson (2001) are credited for an attempt to offer a holistic view on children's needs that moves beyond a focus on one aspect such as physical needs. However, as comprehensive as Loenin-Voysey and Wilson's list is, a

question remains as to whether these needs are unique to orphans and vulnerable children. In fact, most of the needs, if not all, apply to all children regardless of vulnerability.

In addition, the extent to which the identified needs are idealistic and what can feasibly be met in resource-limited communities in contemporary South Africa, is highly questionable. In South Africa, a lot of people who are living in dire poverty cannot adequately meet most of their needs, regardless of whether they are vulnerable or not.

Whilst there is an acknowledgement that Loening-Voysey and Wilson's (2001) list covers a substantial number of needs of children, the fact is, it was developed before the epidemic reached its current scale and before ARVs had been rolled out. Accordingly it is now of limited value. It does not include the essential needs that emerged after the provision of ARVs. For example, children who are HIV positive are at a higher risk of having developmental delays (Kvalsvig *et al.,* 2007) and for this reason additional interventions intended to address these needs, have been developed.

Other than clinical needs, recent studies have attempted to identify specific needs of vulnerable children, especially those who are HIV positive. Some of these are described in the section below.

2.5.1 NEEDS OF VULNERABLE CHILDREN IDENTIFIED IN RECENT STUDIES

The success of ARVs in the reduction of mortality rates of children has been cited by many researchers (Kvalsvig *et al*., 2007). In the absence of a cure, this is a major success in the management of the disease. However, as stated earlier, children who are HIV positive have a higher risk of having developmental delays and there is a need to arrest some of these delays. Kvalsvig *et al*. (2007*)* suggest the following steps as essential:

- "Early identification so that ART can help to contain the damage wrought by infection, poverty, poor nutrition, stigma and the orphaning process;

- Special assistance to build their confidence and capabilities after harsh early experience because they have lost precious development opportunities; and
- There may be residual neuro-developmental disorders which will require special education facilities" (Kvalsvig *et al.*2007: vii).

According to UNICEF (2008) stimulation programmes are important in assisting vulnerable children to develop fully so that they can reach and accomplish certain milestones.

> "Stimulation can be defined as providing interest or increasing alertness of the mind and body in activity through play; also to goad, or prod and incite one into action and stir up what is latent. It is important to stimulate the development for intellectual, social, emotional, spiritual and physical qualities of a child living with HIV and AIDS. Through play, children learn problem solving, interpersonal skills, communication and other skills integral to success in school and life….Play is truly the work of childhood"(UNICEF, 2008:37).

Whilst there is an argument that every child, whether vulnerable or not, needs education and stimulation, children who are vulnerable, especially those who are HIV positive may need special attention as a result of neurological insults.

UNICEF (2008) states that

> "the energy needs increase by 10% in asymptomatic children and between 50% and 100% in symptomatic children. These children also experience a deficiency in micronutrients. Nutrition therefore forms an integral part of any care plan for children living with HIV and AIDS. Nutrition is also important in the provision of ART to achieve the full benefits" (UNICEF, 2008: 19).

While a child needs adequate nutrients whether vulnerable or not, the above statement claims that children living with HIV/AIDS have increased energy needs compared to

uninfected children (UNAIDS, 2009). This supports the point, raised earlier, that adequate nutrition is important for HIV positive children.

The identification of the above needs is important for understanding the care that is required to meet children's needs. The next section starts by defining care and identifies the types of care that address the needs of vulnerable children. In addition, it unveils some models of care and the concepts that assist in the understanding of care.

2.5.2 SOCIAL CONTEXT IN WHICH MANY HIV/AIDS VULNERABLE CHILDREN ARE LOCATED

With very little success researchers have attempted to find a distinction between the needs of vulnerable children and those who are not vulnerable. For the most part, the needs of children rendered vulnerable by HIV/AIDS are similar to those who are not.

Furthermore, recent studies identify mainly biological and developments needs as specific needs of vulnerable children (Kvalsig *et al.*, 2007 & UNICEF, 2008). The researcher supports, based on literature, that other than biological needs, there are no peculiar needs of vulnerable children which necessitate a particular kind of care.

However, literature reveals that the social context in which many children are rendered vulnerable by HIV/AIDS is of more importance to the reconceptualisation of care. According to Van Donk (2002) the impact of HIV/AIDS and the rate of infection is not evenly distributed amongst the South African population. Research has shown that socio economic inequality items: wealth, employment, property and access to material goods and cultural products is central to central to how diseases spread and impact families (Gibbens, 2003 *In* Gilbert *et al.*, 2008). In South Africa and around the world the impact of HIV/AIDS is mainly felt among the black, unemployed, poor and previously marginalised groups (Van Donk, 2002). Van Donk (2002) states that poverty which engulfs most people in this social group accelerates ill health and death due to HIV/AIDS. These contribute to the loss of household income, assets and also increases the burden of care for children infected and affected by the disease. Therefore in the context of HIV/AIDS, the social

context is central to child vulnerability and to the need of care for the children. Therefore in the quest to find out how best to address the complex socio-economic context of this epidemic reconceptualisation of care has become very important.

2.6 DEFINITION AND CONCEPTUALISATION OF CARE

The most important question for this study is: How is care conceptualised to meet the above dimensions, characteristics of the disease, and needs of children in the context of HIV/AIDS?

Different definitions of and approaches to 'care' have been provided by scholars. It is, therefore, important to explore how care has been defined and understood so that an understanding of how these definitions and approaches to care have shifted and changed as a result of HIV/AIDS can be provided.

'Care' has been defined as taking charge of, custody of or responsibility for raising children (in the case of a child) and the well-being of an individual (Boon *et al.,* 2009). D'Cruz (2002 in Makape, 2008:23), defines care mainly in physical terms, as "custodial, maintenance help or services rendered by a family member for the well being of relatives who cannot perform such activities by themselves". In this study these definitions were used to compare these with how Cotlands conceptualises care in the context of HIV/AIDS. However, even though the above definitions of care are useful, the researcher found them limited due to the fact that they do not cover the different types of care. Therefore, the following section addresses this limitation by exploring the types of care provided to HIV/AIDS vulnerable children.

2.6.1 TYPES OF CARE PROVIDED FOR HIV/AIDS-VULNERABLE CHILDREN

Whilst all vulnerable children in the context of HIV/AIDS may have similar needs, some needs may differ depending on whether the child is infected or not. The following types of care have been identified as being essential for children infected and affected by HIV/AIDS. These types of care can, despite their situation, enable children to achieve an optimal quality of life, to enhance their growth and development, and to minimize suffering through mobilizing clinical,

psychological, spiritual, economic and social care (WHO, 1990; Richter & Sherr, 2008). Each of these is elaborated on below.

Clinical care is generally provided by medical professionals including nurses, doctors, psychotherapists, midwives, clinical officers, community and volunteer health workers, traditional healers and physicians (Van Dyk, 2008). In addition to routine healthcare requirements, the services they provide, include: "routine CD4 counting; confidential HIV counselling and testing; routine follow-ups to determine the optimal time to initiate ART; prevention and treatment of opportunistic infections such as tuberculosis; HIV prevention and behaviour-change counselling; alleviation of HIV-related symptoms and pain; support for those who may be severely malnourished; and support for adherence to anti-retroviral therapy (ART)" (Van Dyk, 2008:34).

End-of-life and bereavement care is provided to the individual and family members in need of intensive management of symptoms and pain (Van Dyk, 2008). They include culturally appropriate end-of-life care and bereavement interventions which may include counselling and assistance with burial, succession planning (inheritance), will writing and administration, and making appropriate arrangement as to who will continue caring for children who will be left behind (Van Dyk, 2008; Richter & Sherr, 2008).

Psychological care addresses the non-physical suffering of individuals and family members infected and affected by HIV/AIDS which may include emotional, mental health counselling (Richter & Sherr, 2008); "family care and support groups; support for disclosure of HIV status; bereavement care; development and implementation of culture- and age-specific initiatives for psychological care; and treatment of HIV-related psychiatric illnesses, such as depression and related anxieties" (Van Dyk, 2008:35).

Spiritual care has been identified as essential in helping people infected and affected by HIV/AIDS to deal with loss, trauma and guilt (Richter & Sherr, 2008). It helps them find their purpose and meaning to life. It is important that administers of care are sensitive to culture, religion(s) and rituals of individuals and communities. This is most important in South Africa where there are people with diverse cultural and religious beliefs. Care may include going to

church, “life review and assessment; counselling related to hopes and fears, meaning and purpose, guilt and forgiveness; and life-completion tasks” (Van Dyk, 2008:35)

Social care assists individuals and family members in maintaining linkages to and use of care, preventing HIV infection, and ensuring adherence to treatment (Richter & Sherr, 2008). These can include community-based support groups; community mobilization and leadership development; efforts to reduce stigma; legal services to assist with succession planning, inheritance rights, and legal matters; and assistance with school fees and uniforms.

Economic care is provided to relieve individuals and families from poverty. This can be in the form of social security grants, income generating projects, donations and food support (Mathambo & Richter, 2007).

Richter & Sherr (2008) support a form of comprehensive care that integrates most, if not all the above-mentioned types of care to ensure that children’s health, social and psychological needs are met. Pringle (1980, *In* Loening-Voysey & Wilson, 2001:13) argues that “if any one of these needs remains unmet – or inadequately met – then development may become stunted or distorted”.

However, in South African there is “55% (10 million children) of children belong to households living under the ultra-poverty line of R800 or less a month” Kvalsvig *et al*., 2007:2). In this regard, the feasibility of these children being provided by their families with all the above-mentioned needs is highly questionable. In such resource-constrained environments, families are only able to provide care based on how important it is for survival, such as food, clothing and shelter. This implies a hierarchy of needs instead of the comprehensive care proposed by Richter and Sherr (2008). In addition, cultural beliefs also determine care provided and who provides the care. For example, 80% of the South African black population make use of traditional healing, and spiritual healing (Gilbert *et al.,* 2010). In such cases, the African population rarely make use of psychologists and counsellors to address their psychological problems. This research investigates the extent to which care is provided by Cotlands to families that are unable to provide adequate support and the extent to which care provided by Cotlands takes account of people’s cultural issues.

Having outlined the types of care needed to meet the needs of vulnerable children, it is important to explain how patterns of care have changed as a result of HIV/AIDS. This includes an explanation of the different approaches or models of care.

2.6.2 CHANGES IN CARE PATTERNS

For the past several decades scholars, academics, researchers, activists and medical practitioners have developed a rich body of thinking in the field of care or care-giving (Godorn, Benner & Noddings, 1996). As a result, many theories, concepts and models have been developed in an attempt to explain the meaning of, and approaches to care, in the context of HIV/AIDS and other chronic diseases. With the growing number of people made vulnerable by the epidemic, especially orphans, there has been an increasing demand to apply these theories, concepts and models of care so as to find effective ways of dealing with the challenges posed by the epidemic. Models include institutional care and CBC.

As far back as 1981, theorists like Wing (1981) were already advocating for a community care system to ensure a decent quality of life for chronically ill people and for their relatives, as opposed to institutional care. In institutional care children, in large numbers, are provided with a paid caregiver, and CBC is care that is provided for children by their communities (Rayneke-Barnard, 2005; Ncama, 2005). It is important to note that care for vulnerable people, whether they are best cared for in institutions or in communities, was debated long before the serious social impact of HIV/AIDS that we have today. However, more than any other disease in history, HIV/AIDS has caused the breakdown of families and community structures. In addition it has led to millions of children being orphaned and made vulnerable (Boon *et al.*, 2009). The need to address these impacts and the resultant vulnerability of children have heightened and added complexity to the debate on models of care. More than ever before, there is a need to find the most effective model(s) of care that can address the social impact of the disease.

Numerous studies have revealed that institutional care, though it is used in South Africa and world-wide, is not able to meet the social and psychological needs of vulnerable people (Johnson *et al.*, 2006; Tolfree, 2003; Boon *et al.*, 2009). As a result, there is growing pressure for organisations to move away from providing institutional care and to provide care that is considered to be more conducive for brain growth, attachment, social behaviour, cognitive functions and the socio-economic development of vulnerable people (Johnson *et al.*,2006; Tolfree, 2003).

The South African government stated that it is strongly in support of CBC rather than institutional and statutory foster care. In 2002, according to Loening-Voysey and Wilson (2002:63) the government pledged that it had "decided to scale up family and community support mechanisms and scale down institutional care". Hence the government and other international bodies such as WHO urged NGOs and other organisations involved in the provision of long-term and/or short-term care to shift away from the provision of institutional care to CBC (Rayneke-Barnard, 2005). In this regard, this study intends to investigate the models of care used by the chosen organisation and the reasons why it uses such models. It is also essential to explore the model of care debate itself and the changes in the patterns of care so as to gain an understanding of the most effective model(s) of care from the researcher's and Cotlands' perspective. An effective model that can holistically address the challenges and meet the needs of people made vulnerable by HIV/AIDS is required.

Model of care debate Models of care vary in both the quality of care offered and the cost of providing it (Desmond & Gow, 2001). The capacity of models of care and their effectiveness in the provision of the necessary care has been highly challenged by HIV/AIDS. The following discussion draws on empirical studies conducted in China, Malawi, Zimbabwe and South Africa to compare the models of care (Desmond & Gow, 2001; Beard, Beard, Dimmock & Sthreshley, 2002; Hong, Li, Fang, Zhao, Zhao, Zhao, Lin, Zhang & Stanton, 2010).

Institutional care model

Institutional care, also referred to as residential care, is "a group living arrangement for children in which care is provided by remunerated adults who would not be regarded as

traditional care-givers within the wider society" (Rayneke-Barnard, 2005:23). Tolfree (2003:7) also states that "institutional care involves large numbers of children living in an artificial setting." Institutional care aims at providing either temporary or permanent care to children for various reasons such as a child being orphaned, a child from a seriously unstable home, a chronically ill child and so on. Orphanages and child villages are the major types of institutional care models (Beard *et al.,* 2002). Traditionally, orphanages are mainly dormitory-based children's homes, where children are separated by age and sex, and share communal living and dining areas (Reed, 2001). On the other hand, child villages are family-based children's homes which imitate a normal family where children stay in smaller units with one parental figure (Reed, 2001)

.

The existing literature presents many arguments against institutional care. These arguments existed long before HIV/AIDS. Early studies that demonstrated the negative effect of institutional care on child development include Golfard (1945), Spitz (1965) and Bowlby (1969). These researchers argued that institutional care has an irreparable effect on children's social, intellectual and emotional behaviour and hence children should be kept out of institutions (Morrison, 2008).

Furthermore, a growing body of global research shows that the institutional model of care presents great social and psychological risks for young children (Beard *et al*., 2002). Among these risks is the reduced ability to form lasting attachments, community stigmatisation, and transitional issues related to housing, education, and employment when children eventually leave the institutions (Beard *et al.* 2002; Hong *et al.,*2010). Other critics of institutional care make reference to the fact that they are very expensive; they can only accommodate a small percentage of all children in need of care and they may undermine what families and communities are doing (Boon *et al.,* 2009). A more comprehensive critique of institutional care is offered by Tofree (2003) who presents a seven-point analysis of the typical negative features of institutional care. He argues that these features have a negative impact on both child development and on children's rights. These seven-points include:

> "the segregation, discrimination and isolation that institutionalised children often experience; the fact that admission is often based on the needs of parents, not the interests of children; the lack of personal care and stimulation; the lack of opportunities to learn about the roles of adults; the high risk of institutional abuse; the lack of attention to specific psychological needs; and finally, reflecting all of these features, the fact that institutionalised children often experience problems in adjusting to life outside of the institution" (Tofree, 2003:5).

Many studies have been conducted into the psychological and social impact of institutional care on children. Amongst these, a study by Johnson *et al.* (2006) in which they reviewed 12 studies that specifically considered the formation of emotional attachments for children in institutions compared with other non-institutionalised children. Only one study (of the twelve) found no supporting evidence for greater attachment difficulties for children growing up in residential care. "Nine studies report significantly more indiscriminate friendliness, over-friendliness and/or uninhibited behaviour for children in institutions, suggesting 'disorganised attachment disorder' has greater prevalence among these children compared to children in families or to children who were admitted to institutional care after the age of two years" (Brown, 2009). Such behaviour was attributed to the low care-giver-to-child ratios which inhibits meaningful social interaction.

Extremist views of institutional care argue that it has a life-long and irreparable impact on children (Vallende & Fogelman, 1987). Hence, authors such as Vallender and Fogelman (1987) argued it should never be used. They pointed out that

> ''..perhaps (the) more lasting and pervasive impact of institutions, is the loss of a sense of identity. There are three basic questions to which, all too often, the child receives no answer: Who am I? Why am I here? And where am I going? Not only does the child in long- term care have no reliable past; equally devastating, he has no predictable future, except that he will come out of care at the age of eighteen...institutions should be not be expected to provide substitute parental care

> either on a short or a long-term basis. Neither should they be considered suitable placements for children while appropriate long-term plans are being worked out nor, worst of all, as a 'last resort' because no other alternatives are available or have not yet produced the desired results" (Vallander & Fogelman, 1987:67-70).

Very few authors cited positive effects of institutional care on children. Those who cited strengths of institutional care argue that it provides emergency care for very ill children who are difficult to place (Desmond & Gow, 2001). Others state that due to the centralised nature of institutions, children living in a well-controlled and monitored environment such as institutional care have a higher chance of having their physical needs met than those who are in community-based care (Morrison, 2005).

Desmond and Gow (2001) argue that, in the context of HIV/AIDS, there is still a role institutional care can play. They argue that institutional care can be used as a 'last resort' for vulnerable children with no other option (Beard *et al.*, 2002; Desmond & Gow, 2001). There are cases where a child loses both parents to HIV/AIDS and has no other relative. Beard *et al.*, (2002) and Desmond and Gow (2001) argue that in such cases, institutional care may have to provide temporary support for vulnerable children with no one to care for them.

As a result of the fact that much of the research has shown the negative effects of institutional care such as in orphanages where many children live in a single dormitory, babies spend most of their time lying in their beds and children eat in cafeterias, attempts have been made to improve institutional care (Beard *et al.*, 2002). Such improvements include the introduction of the child village model. According to Beard *et al.* (2002:2) "child village models try to emulate a normal family environment for the orphans by grouping them as family units under the care of a paid guardian. These family units are clustered in a village-like setting." To a large extent, the child village model tries to provide orphans and vulnerable children with no relatives, with a relatively normal home environment (Beard *et al.*, 2002).

However, whether the institutional care is in the form of orphanages where many children live in a single dormitory; or child villages which try to imitate family settings, institutional care as

a whole has been highly been criticized. Many critics of institutional- based care ignore factors that lead to child vulnerability that may have contributed to a child being institutionalized. In cases where a child has no one else to care for him/her, he/she is better off being provided with institutional care. Furthermore, in a case where a family might neglect or endanger a child, the child is better off in the institution. In addition, in the context of HIV/AIDS, many children are left with no one to care for them, and foster care is limited. If institutional care is prohibited, these children would be left with no one to care for them.

Community-based care

The negative effects of institutional care on a child's development and its inability to accommodate the millions of children rendered vulnerable by HIV/AIDS are some contributing reasons for the increased advocacy for CBC worldwide. According to Ncama (2005: 33) CBC can be defined as "care that the individual can access nearest to home, which encourages participation by the people, responds to the needs of people, encourages traditional community life and creates responsibilities".

Research reveals that extended families and kinship networks have always been the first in line to respond in terms of caring for the orphaned and vulnerable children (Gordon *et al*., (1996). However, there was also a higher tendency to place children from seriously under-resourced families, abandoned and orphaned children without relatives in institutional care (Rayneke-Barnard, 2005)

According to Ncama (2005) the concept of CBC is relatively new in the African context where the continent mainly made use of the institutionalised model to care for children. Ncama (2005) points out that home-based programmes mainly for people living with HIV/AIDS were mostly initiated in North America and Europe in the late 1980s. This model was considered as the most comprehensive and cost-effective in caring for such people. The massive numbers of children rendered vulnerable by HIV/AIDS in the 1990s in Africa overwhelmed the traditional mechanisms (families and extended families) of care. In addition institutional care became too costly to accommodate all the children in need of care. Hence, more than ever before, there is an increased advocacy for CBC. The CBC model includes home-based care, home visiting

programmes and activities such as support groups, community mobilisation, income-generating projects and so on. A support group is a group of people who meet regularly to support or sustain each other by discussing problems affecting them in common, and community mobilization involves developing community action around community issues (Ncama, 2005: 35).

Foster care is also another form of CBC which is being urged to be used instead of institutional care. Foster care is defined by Colton & William, (1997:44) as care provided in the care-giver's "home, on a temporary or permanent basis, through the mediation of a recognised authority, by specific carers, who may be relatives or not, to a child who may or may not be officially resident with the foster carers." Studies reveal that foster care has greatly expanded in recent years. (UNICEF, 2008). Data from the South African Social Security Agency shows that, by 2008, close to half a million children were in formal, court-ordered foster care. In addition, the quest for finding more effective ways of caring for millions of people rendered vulnerable by HIV/AIDS has further urged for care that can meet the economic, social and psychological needs of the vulnerable (SA UNICEF, 2008). As a result a new approach to care, cluster foster care, is being adopted by South Africa (Government Gazette of the Republic of South Africa, 2008). Whilst this approach might have existed for a long time in the developed countries, in South Africa, cluster foster care, whereby a group of women or couples collectively agree to care for children, is less common although it is on the increase. According to the Government Gazette of the Republic of South Africa (2008: 183) in cluster foster care there "are a group of caregivers who are linked together to provide mutual support in the care of a number of children and who receive some form of external support and monitoring."

Arguments for CBC, in the context of HIV/AIDS, include its ability to cater for a large number of children at a low cost. This is because in cases where there is shortage of man power to care for vulnerable children, organisations are able to make use of individuals from indigenous resources such as grandparents and extended families in order to address the children's problems realistically and effectively (Rayneke-Barnard, 2005).

Linked to the above point is the fact that community care strategies support informal, indigenous and traditional ways of caring for children in need of care. There are assumptions by researchers that extended families and kinship networks are able to provide better care services to vulnerable children than institutional care (Desmond & Gow, 2002; Beard *et al.*, 2002; Hong, 2010). "The fundamental value that underpins the general functioning of African people and kinship networks is Ubuntu" (Mashologu-kase, 2005:7 *In* Rayneke-Barnard, 2005). In this context, it is viewed as a more culturally appropriate model which allows the children's psychosocial needs to be better met (Desmond & Gow, 2001; Beard *et al.*, 2002). By not removing the children from their environment, communities' values and beliefs are instilled in children and this is crucial for their development into social beings. In addition it is argued that children are able to receive love and affection when kept with their siblings and relatives (Beard *et al.*, 2002). For the most part, the above assumptions reflect cultural essentialism which is problematic because a possibility consequence of blocking other potential helpers who may not possess similar characteristics as the children. The fact that the caregiver or helper may share the same characteristics (including ethnicity) does not necessarily mean that the caregiver would provide better care than someone who is deemed culturally different.

Desmond and Gow (2001), state that at the core of this approach are self-help activities for income generation and community development (Beard *et al*., 2002). These activities can be used to empower families by making them self-reliant and in the long run, families are empowered to be able to identify and solve their own problems. This is very important for the sustainability of care for the vulnerable children. In addition, programmes such as support groups are reported to "build self-confidence, help people cope with their diagnosis, overcome depression and create social networks for people who are isolated and assist people in finding ways to solve their own problems" (Russel & Schneider, 2000;330). There also arguments that bonds that are formed at the social group can help with issues such as disclosure, getting people tested and sharing of information (Binagwaho & Ratnayake, 2009).

Even though, this model is regarded as the most effective, it has some flaws. A major disadvantage of this model is that because of its decentralized nature, it is very difficult to monitor. In addition, failure to plan, manage, control and monitor a community-based care

model may result in children falling through the safety nets and having to fend for themselves (Beard *et al.*, 2002). Many researchers cite mainly the positive aspects of community based care and very few challenges were noted.

To a large extent, as has been pointed out already, most of the above-mentioned authors assume that communities are homogenous, that is they are held together by the spirit of 'Ubuntu' (Beard et al., 2002; Rayneke-Barnard, 2005). These scholars ignore individual differences that may bring challenges in terms of insuring that the child's needs are met. In addition, Beard *et al.* (2002) have made a generalized claim that children are able to receive love and affection in their families. In reality, it is not always the case. Parents can abuse, endanger and neglect their own children. Those who argue for CBC and for the abolition of institutional care assume that extended families will always be able and willing to care for a child if he/she has no caregivers. There are cases where extend families are not available or are not willing or are overwhelmed so much that they are not able to care for a vulnerable child. In a case where a child has no one to care for him/her institutional care is needed.

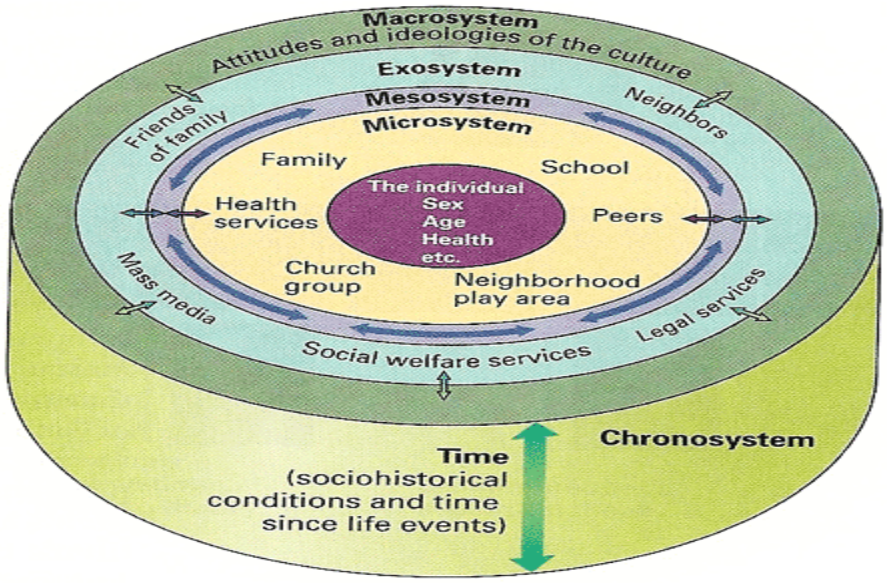
Caring for people made vulnerable by HIV/AIDS is clearly a complex task with resources having to be divided to deal with the problem. From this point of view, the above models of care and the debates around their effectiveness are important for understanding the models being used by Cotlands, and the justification for their use. This also helps to determine the most effective model of care that addresses the challenges of the epidemic.

Brofenbrenner's Ecological Systems Theory and the importance of CBC

A number of theories have been developed to explain the importance of community involvement in child care and child development. Hence, in order to have a better understanding of the concept of community based care (CBC) and its importance in dealing with some of the challenges in the context of HIV/AIDS, it is crucial to explore one of the most influential theories: Brofenbrenner's Ecological Systems Theory.

Although many theories from various disciplines have enriched the field of child development over the decades, Brofenbrenner's Ecological systems theory has been one of the most influential sociological theories, and has been found to be important for this study. The theory implies that care intervention cannot effectively be implemented in isolation of the child's environment (community) (Harris, 1989). It places emphasis on the immediate environment including family, school and neighbourhood and the broader society which includes norms, laws and values as having a strong impact on a child's development (Paquette & Ryan, 2001). These systems contribute to the child's development which involves a reciprocal complex interaction between the child and all levels of environmental influences (as shown in figure 1 below).

Figure: 1 Diagram illustrating the interaction between an individual and his/her environment



(Santrock 2007 *In* Paquette & Ryan, 2001:1)

Brofenbrenner's ecological systems theory identified five systems that are important for a child's development: microsystem, mesosystem, exosystem, macrosystem and the chronosystem.

Firstly, the microsystem comprises the immediate surroundings including the child's family, school, neighbourhood and religion with which the child has direct contact. These structures "directly influence the child's behaviour, beliefs and development" (Paquette & Ryan, 2001: 2). Secondly, the mesosystem provides the connection between the structures of the child's microsystem which may include, a child's school and family (Bronfenbrenner. 1979). Thirdly, the exosystem is a much larger layer which defines the social system in which the child does not function directly. Even though the child does not have a direct and active role with his/her social setting he/she feels positively or negatively involved in the interaction with his/her own system. For example a parent's attendance of a social group that helps him/her to deal with HIV/AIDS, the parent may gain knowledge that helps him/her and the child. Fourthly, the macrosystem represents the cultural environment in which the child resides. It comprises cultural values, customs and laws (Bronfenbrenner. 1979; Berk, 2000 *In* Paquette and Ryan, 2001). Lastly, the chronosystem represents the pattern of events over time, or the dimensions of time as they relate to a child's environment. The model stipulates that child development results from interactions between the child and their families, schools communities and their broader society over time.

According to Van Dyk (2008:210) "community plays a very important role in traditional life in Africa". Hence, the ecological system theory acknowledges that an individual cannot exist alone but rather that "personal identity is totally embedded in the collective existence" (Van Dyk, 2008:210). Mbiti (*In* Van Dyk , 2008: 210) states:

> "...when an individual suffers, he does not suffer alone but with the corporate group; when he rejoices, he rejoices not alone but with his kinsmen, his neighbours and relatives whether dead or alive. Whatever happens to the individual happens to the whole group, and whatever happens to the whole group happens to the individual. The individual can only say: I am because we are; and since we are therefore I am".

For every child born with HIV there is a mother and/or a father who is positive, and for every mother and father infected with HIV there is a child affected. Therefore, one of the major critics of institutional care is its removal of a child from his/her community and the

exclusion of a family from child care. CBC acknowledges the co-existence between a child and his/her community or family. HIV/AIDS cannot be addressed in isolation from the family, social, cultural, economic physical environment in which a child resides (Madzingira *et al.*, 2008).

Having defined care, identified types of care and models of care for vulnerable children, it is important to explain some concepts of care. The next section, explains concepts of care including social reproduction and social capital.

2.6.3 IMPORTANT CONCEPTS OF CARE

Theories, concepts and issues that effectively explain care and the need for care in the context of HIV and AIDS include: social reproduction and social capital.

Social reproduction

As stated earlier, the essence of 'care' is in part to enable people to fulfil their social roles. Care is crucial for securing the daily and generational reproduction of society (Ansell, 2008). In this regard, the concept of social reproduction can be used to explain the need for caring for vulnerable children.

Before exploring the concept of social reproduction, it is of utmost importance to distinguish between 'social reproduction' and 'care'. Even though 'care' is an essential component of social reproduction, the two concepts are not the same. Whilst 'care' is restricted to only those who depend on others and those who may not be able to fulfil, for the most part, their economically active functions, social reproduction is applied to every individual in the society (Kofman 2005 *In* Makape, 2008). It refers to the daily activities that ensure that all people survive and that skills, knowledge and values are passed from one generation to another (Ansell, 2008). As a result of the fact that 'care' is regarded as a very important part of social reproduction, an understanding of whether or not Cotlands' re-conceptualisation of care includes social reproduction and in what ways becomes of key importance.

According to Ansell (2008) social reproduction is a broad concept and has been approached in different ways. There are those who define it mainly in terms of work of production, whilst others define it in terms of processes that lead to generational change and continuity. The following varying definitions of social reproduction have emerged: "the interdependent reproduction both of the social relations within which, and the material and discursive means through which, social life is premised, sustained and transformed over time" (Lee 2000:760 *In* Ansell, 2008: 803) or: "material and social practices through which people reproduce themselves on a daily and generational basis" (Katz 2001:711 *In* Ansell, 2008:803). Brenner and Laslett (1986 *In* Makape, 2008:22) define "social reproduction as the activities and attitudes, behaviours and emotions, responsibilities and relationships directly involved in the maintenance of life on a daily basis and inter-generationally." In both of these definitions, the concept is defined as a diverse and dynamic process which involves material and social procedures that are targeted at continuity and change in a society. Social reproduction is "fundamentally about on-goingness over time, and while it concerns people's daily health and welfare, it simultaneously incorporates the long-term reproduction of a labour force" (Aitken *et al*., 2006, *In* Ansell, 2008: 803).

The definitions of social reproduction reveal that it is a dynamic process. Therefore, rapid social changes can occur which can negatively impact on the society's ability to reproduce itself. In history, other than war, HIV/AIDS is said to have caused the most serious breakdown in social reproduction, with specific reference to the diminishing labour force and the diminution of instillers of knowledge and skills in children (Ansell, 2008). As a result of this, mechanisms for transferring knowledge, skills, values and beliefs from one generation to another are greatly disrupted by HIV/AIDS. In this regard, social reproduction is undermined as the disease has generated irreversible collapse of the social, economic and reproductive asset base (Villarreal, 2006). This discussion helps us understand why it is important to consider those affected, not only those infected.

According to Barnett and Whiteside (2000:52) the following are the symptoms of the disintegration of social reproduction:

- breakdown of caring arrangements for children and the elderly;

- failure of the informal education system;
- decline of child-care standards; and
- decline in informal knowledge base about values and goals of local communities and households.

With the above understanding of social reproduction, this research investigates what Cotlands is doing with regards to bridging the gap that has been created by HIV/AIDS in terms of transferring knowledge, skills, values and beliefs from one generation to another. It investigates the extent to which Cotlands' re-conceptualisation of 'care' constitutes the restoration of social reproduction.

Directly linked to social reproduction is social capital. Social capital can be used to empower people who are vulnerable in the context of HIV/AIDS so that they can be socially reproductive. It is important, consequently, to explore the concept of social capital and how it can be used to benefit vulnerable children in the context of HIV/AIDS.

Social capital

No one person or organisation can address all of the care needs of vulnerable persons, in the context of HIV/AIDS, without the involvement of other people (Madzingira *et al.*, 2008). This statement evokes the need for social capital in effectively caring for the vulnerable. As Carpiano (2006:165) states, "conceptualisation of social capital consist of features such as interpersonal trust, norms of reciprocity, and social engagement that foster community and social participation and can be used to impact on a number of beneficial outcomes, including health". This conceptualisation of social capital demonstrates the broadness under which social capital can be studied.

Currently, there is no universal conceptual definition of social capital. Scholars have provided definitions that are have controversial statements (Hawe & Shiell, 2000). This problem of definition can be reviewed by briefly exploring the theories that attempt to define social capital which are also used to depict the relationship between social capital and care. These theories include those put forward by Durkheim, Bourdieu and Putman amongst others.

Putman defines "social capital as features of social organisation, such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit" (Putman, 1995:67 *In* Carpiano, 2006:166). Putman's definition is criticised for deviating from traditional social science which defines social capital as resources derived from a social capital network (Carpiano, 2006). Unlike Putman who deviated from the traditional definition of social capital, Bourdieu's theory and studies emphasise the resource-based nature of social capital. He defined social capital as "the sum or aggregate of resources, actual or virtual, that accrue to an individual or group by virtue of processing a durable network or more or less institutionalised relationship of mutual acquaintance and recognition" (Carpiano, 2007:23).

Despite the controversies around defining and theorising about social capital, studies have revealed that networks or social groups can be used to create effective support or care for people made vulnerable by HIV/AIDS (Binagwaho & Ratnayake, 2009). Jamil and Murrisa (2004: 4) reveal that through "solidarity mechanisms, namely a series of networks, groups and organisational formations, peoples' capacity is strengthened." Collective action has made many people infected and affected by HIV/AIDS manage stigma, social exclusion and to address issues of prevention and control. Jamil and Murrisa (2004) also state that social capital has a potential to reduce HIV transmission and spread, mortality and stress.

A study by Binagwaho and Ratnayake (2009) can be used to support the above arguments. Binawaho and Ratnayake (2009) investigated why Africans are increasingly adhering to ARV therapy more than people in North America despite the fact that Africans have lower education about the disease compared to the North Americans. Their study found social capital to be higher and to play a more significant role in African communities compared to those in North America.

This study intends to investigate whether or not social capital constitutes part of Cotlands' caring mechanisms, whether or not it is providing benefit and how it could be used to re-conceptualise care in the context of HIV/AIDS.

2.7 FAMILY RESPONSES TO VULNERABLE CHILDREN

As has been pointed out, statistics estimate that 3.3 million children in South Africa have lost at least one parent to HIV/AIDS (USAID, 2007). The question as to who bears the burden of caring for these children is posed. Ideally, family has always been responsible for care and the upbringing of children. However, as stated by Smit (2007:165) " the HIV and AIDS epidemic and the shift in the patterns of care, especially adult mortality have clear implications for the structure of family and household in South Africa". This questions the family's ability to cope in terms of caring for the vulnerable children. Hence, in order to understand the degree of and the need for NGOs involvement in caring, it is important to discuss the impact of HIV/AIDS on care provided by families and communities, and the government and NGO responses to these challenges.

As stated earlier, one of the unique characteristics of HIV/AIDS is that the majority of the people succumbing to the disease are in the economically active category of between 20 and 40 years (Bendix, 2007; Barnett & Whiteside, 2001). Among these are a large number of highly skilled and qualified persons (Bendix, 2007). Death or sickness of these people, who are also breadwinners /or caregivers has damaging effects on dependents, and on those who are left to care for the sick and orphans (Foster and Williamson, 2000).

South Africa, like any other African country, is regarded as having a culture that is more collective as opposed to being individualistic (Gilbert *et al.*,2010). This collective cultural approach to problems is reflected in Africa's coping and caring mechanisms in response to HIV/AIDS. As Foster and Williamson state (2000: 278), 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. Hence, one of the most profound impacts of HIV/AIDS is on the family structures (Smit, 2007).

Smit (2007) identified four impacts of HIV/AIDS on family and household structure. These include the increase in single parent families, grandparent-headed households, child-headed households and extended families.

Single parent family structures have existed for a long time in South Africa. These structures represent the legacy of Apartheid where men were mainly forced by circumstance to leave their families and work in mines situated in urban areas (Gilbert *et al.,* 2010). However, single parenthood has increased as a result of, firstly, a spouse deserting his family after knowing his HIV status (Smit, 2007). Secondly, the high adult mortality rate due to HIV/AIDS has left a single parent to fend for the children (Smit, 2007).

In African customs, grandparents have always been considered important for children's socialisation. However, HIV/AIDS has introduced an era where grandmothers are taking full responsibility for care-giving. This is "where gogo(es) [grandmother(s)] are becoming mothers again" (Smit, 2007:167). These are in cases where both parents of a child have died or are incapacitated by HIV/AIDS.

There are also cases where there are no grandparents or where the grandparents are not able to care for the children. Older children, some as young as 12 years old have taken the responsibility of caring for their younger siblings. More than ever before, HIV/AIDS has escalated the number of child-headed families. It is reported that over 98 000 children in South Africa live in child-headed households (Jones, 2011). To fend for their siblings or to care for their dying parents, these children have had to drop out of school. They have had to involve themselves in income generating activities such as prostitution, street vending, hawking, petty theft and begging (Smit, 2007: 167).

Lastly, traditionally extended families have always made it possible for care to be extended beyond nuclear families, especially in cases where the nuclear families are unable to support its children (Smit, 2007). However, the need for nuclear families to seek help from extended family has intensified in the context of HIV/AIDS. These extended families have "had to care for families suffering from AIDS and their dependents" (Smit, 2007: 168).

As the impact of the disease intensifies, the massive numbers of people affected and infected by HIV/AIDS have overwhelmed the above traditional or kinship-caring mechanisms (Villarreal, 2006). This has greatly contributed to the need for government and NGOs'

involvement in the caring for the people orphaned and made vulnerable by the disease. Below is an explanation of how the South African government has attempted to assist the families and communities in caring for the vulnerable. This will help in understanding the need for NGOs' involvement in assisting both families and the government.

Family and community responses are considered by far the most effective ways of responding to the need to care for vulnerable children in the context of HIV/AIDS (Foster, 2002). This is because these children can be kept in their social spheres, which is vital for their psychosocial development. However, as stated by Foster (2002:79) "where family and community networks fail, become overburdened or require supplementing, the state is often the final port of call."

2.8 GOVERNMENT RESPONSES TO VULNERABLE CHILDREN

One of the main roles of most governments is to offer social security to its people. According to Kasente (2000), *In* Makape, (2008: 21) "the International Labour Organisation defines 'social security' as the protection which society provides for its members through a series of public measures against the economic and social distress that otherwise would be caused by the stoppage or substantial reduction in earnings resulting from sickness, maternity, employment injury, invalidity and death; the provision of medical care and the provision of subsidies for families with children."

In most African countries, one of the ways in which governments are playing a role in caring for people made vulnerable by HIV/AIDS is through the provision of social security. Governments have built hospitals, homes and orphanages, provided social grants and have also established a number of other initiatives (Makape, 2008). In addition, governments have formed partnerships with NGOs and families to respond to the epidemic. However, compared to the magnitude of the problem, the South African government, like other African governments, is playing a relatively minor role (Makape, 2008).This is, in part, due to lack of funds and infrastructure to cope with the increased burden of people in need of care.

The provision of social grants to the vulnerable persons is one of the creditable responses despite some limitations by the South African government to the challenges of HIV/AIDS.

The grants are as follows:

- "The Child Support Grant, which currently targets children under the age of 14. The grant is given to children tested and caregivers are eligible for a grant of 240 a month.
- Foster Child Grant, which is 680, is for children placed in foster care. This grant is received only by children placed in foster care by a court of law.
- The Care Dependency Grant is for children with severe mental or physical disabilities who require permanent home care. The grant is meant for tested children and amounts to a sum of plus/minus R1010 a month. There is no specific provision for children with chronic illnesses such as HIV/AIDS and relatively few children in the terminal stages of the virus have managed to access this grant". (Proudlock & Hall, 2011: 3).

It is reported that, South African Social Security Agency (SASSA), "has managed to reach 10, 274, 444 children aged birth to 14 through the child support grant" (SASS, 2011:8). However, research has revealed that the provision of these social grants to the caregivers (mainly grandparents) and orphans has been ineffective to a large extent. Hlabyago and Ogunbanjo's (2009:506) research revealed:

> "..most caregivers did not know their rights, or those of the orphans as far as the state grants were concerned. Some did not have the necessary documents to apply for state grants and also did not know how to obtain these documents. This problem created great distress among the caregivers…. Bureaucratic difficulties and lack of assistance from the South African social support services has left a lot of caregivers and those in need to the resources (money) unable to access them".

Apart from the challenges revealed from the above statement, corruption amongst the government officials and those administering the social grants has led to some of the social grants not reaching the caregivers and the vulnerable persons (Hlabyago & Ogunbanjo,

2009). All these hinder progress in the provision of care to the children made vulnerable by HIV/AIDS.

The government has also been involved in providing legislative framework for caring for the vulnerable children. This includes the establishment of The Patients' Rights Charter, The Children's Charter of South Africa, and The Children's Bill of Rights and Children's Act 41 of 2007. These Acts including others provide regulations as to how children and vulnerable children should be cared for. The South Africa government also provides funds to NGOs involved in, but not limited to, care for children.

2.9 NGOs Responses to Vulnerable Children

Having outlined the impact of HIV/AIDS on individuals, families and the government, it becomes clear that these entities alone are not able to cope with the demands for caring for vulnerable people. With 3.3 million orphans, a figure expected to rise to 5 million by 2015, (USAID Southern Africa, 2007), the government and the traditional mechanisms of caring for vulnerable persons are, beyond doubt, overwhelmed.

As a result, research has shown that NGOs have had to step in to alleviate the burden by helping care for some of the people infected and affected by the epidemic (UNAIDS, 2009). In this regard, there is a growth in NGOs' involvement in dealing with HIV/AIDS even though the exact number of NGOs is not clear. According to Reed (2008:1) "during the last two decades, non-governmental organisations (NGOs) have enjoyed a period of unprecedented growth", and the most remarkable growth has been in organisations offering HIV-related services. The HIV-Related Service directory reveals that in South Africa there are 14 579 organisations whose focus is to respond to the HIV/AIDS epidemic of which the bulk of them are NGOs.

A number of studies have been conducted to identify intervention by NGOs in the HIV epidemic and also to assess the effectiveness of such interventions. These studies reveal that strategies or responses supporting children infected and affected by HIV/AIDS are varied. Even though they vary, Schenk (2009) was able to identify two main approaches that are being

used by NGOs in their interventions. These approaches are identified as the centralised and decentralised approaches. On the one hand, the centralised approach includes: “supervised day care for pre-school aged children; centralised meals (traditional feeding centres), skills-building and psychosocial counselling for older children; residential care and hospice care and social centres” (Schenk, 2009:920). On the other hand, the decentralised approach includes: “indirect support to a network of day care centres; direct household support through material support, nutritional assistance such as community based therapeutic care, social worker visits, assistance in accessing grants, income-generating activities, school fee waivers and school uniforms” (Schenk, 2009:920).

Each approach has its advantages and disadvantages. As quoted from Schenk (2009:920) the “centralised approach allows for comprehensive outreach, ensures direct benefit from resources, facilitates good quality control; but is labour intensive to scale up. [the] Decentralised approach allows orphans to remain more integrated within their community; reduces costs and facilitates scale-up through use of existing structures; but less control over service quality and benefits”.

Whilst it has been stated that there has been an unprecedented growth of NGOs that offer HIV-related services, studies reveal that the sustainability of some of these organisations is highly questionable (Reed, 2008). One of the reasons is that some organisations have not been able to secure broad-based donor funding nor were they able to partner with other strong organisations or the government (Schenk, 2009). Therefore, these were severely affected by the recession. Furthermore, studies also reveal that fragmented programmes that address the needs of children were less effective than integrated approaches (Murray, 2010).

NGOs have been urged to scale up and expand if they are effectively to respond to the millions of children in need of care (Reed, 2008). From this perspective, even though there are a substantial number of organisations using institutionalised or residential care in South Africa especially in the urban areas, many organisations are moving away from this model of care to community-based care. This is a model that can ensure that as many children as possible are

accommodated at a lower cost and that the children are provided with care that can better meet their psychosocial needs.

This research intends to investigate how activities and programmes offered by Cotlands are different and/or similar to the above mentioned interventions by other NGOs. In addition, this study highlights some of the lessons Cotlands can learn from some of these organisations in its re-conceptualisation of care. Responses by other organisations also provide a platform from which Cotlands' care activities can be evaluated.

This chapter provided a review of characteristics and dimensions of HIV/AIDS, the impact of the disease on children and the needs of vulnerable children. It also unveiled the types of care and some concepts of care such as social reproduction and social capital. This was followed by the impact of HIV/AIDS on families that necessitates the NGOs' involvement. An exploration of the intervention by NGOs in caring for vulnerable children in the context of the disease was then provided. The next section provides the conceptual framework of the study.

2.10 CONCEPTUAL FRAMEWORK

For this study, the operational definition of ***care*** includes both short-term and long-term needs of children and adults. It involves activities that are productive and reproductive, such as child-raising, providing the child or adult with food, clothing, shelter, education, and/or finances, medical treatment, nursing the sick child or adult and so on (Boon *et al.,* 2009). It includes medical, social and psychological needs provided by either formal (mainly paid) or informal (mainly unpaid) caregivers (Boon *et al.,* 2009). These activities include both mitigation and prevention strategies. This definition of 'care' will enable the researcher to explore how Cotlands' re-conceptualisation and implementation of 'care' is congruent with or differs from this. This will be done through assessing particular services rendered by Cotlands, such as care provided within the institution, home-based care, counselling projects and income generating projects.

Gillespie *et al.*'s (2005) categorisation of vulnerable children is comprehensive enough to capture the different and major aspects of the impact of HIV/AIDS on children. Hence, their categorisation listed below was found to be most relevant for this study.

- Vulnerable children who have lost one or both parents to AIDS (maternal, paternal and double orphans) wherever they live, including on the street;
- "Vulnerable children whose parents are alive but who live with relatives or non-relatives under strained capacity (often identified as social orphans);
- Vulnerable children living in households with adult caregivers (parents or non-parents) or other siblings who are chronically ill, possibly due to HIV/AIDS.
- Vulnerable children who are HIV-positive or living with HIV and AIDS, some of whom may be orphans;
- Vulnerable children in poor households who are not orphaned but experience an adult death; and
- Vulnerable children living with their parents in fostering households, which may have recently taken in an orphaned child" (Gillespie, *et al.,* 2005:2)

The above categorisation captures the different aspects of child vulnerability which include orphaned children living with incapacitated or ill parents due to HIV/AIDS, HIV positive children and HIV positive children living in dire poverty.

The operational definition of ***social reproduction*** for this study is provided by Brenner and Laslett (1986, *In* Makape, 2008). They define social reproduction as "the activities and attitudes, behaviours and emotions, responsibilities and relationships directly involved in the maintenance of life on a daily basis and intergenerationally" (Makape, 2008: 22). This definition will be used in understanding how care has been re-conceptualised by Cotlands. This was operationalised by analysing how care activities are maintained and how they impact on lives of children.

The operational definition of ***social capital*** is obtained from Carpiano (2006: 165) who states that "social capital consists of features such as interpersonal trust, norms of reciprocity, and social engagement that foster community and social participation and can be used to impact a number of beneficial outcomes." The beneficial outcomes that this study will focus on include improvements in the health of people living with HIV/AIDS; on increased adherence to ARV therapy; and behavioural change both for those who are HIV positive and who are HIV negative. This definition is broad enough to capture major aspects of social capital which are relevant for this study. The definition will be used to assess the extent to which re-conceptualisation of 'care' by Cotlands includes social capital.

Therefore, care was theoretically conceptualised and measured in terms of the maintenance of social reproduction, and the development and utilisation of social capital. The application of the concept of effectiveness of provision of care was assessed according to the following sub-questions :

1. To what extent do Cotlands' programmes and initiatives cater for the physical, social, economic and psychological needs of the vulnerable children?
2. To what extent do Cotlands' programmes "constitute activities and attitudes, behaviours and emotions, responsibilities and relationships directly involved in the maintenance of vulnerable children's lives on a daily basis and inter-generationally?" (Brenner & Leslett, 1989, *In* Makape, 2008: 22).
3. To what extent does Cotlands provide protection against the economic and social effects of HIV/AIDS? How important is Cotlands' form of social security compared to that provided by families and government?
4. What forms of social capital does Cotlands provide for its beneficiaries? How do these benefit the vulnerable persons economically and socially?
5. To what extent do Cotlands' care mechanisms constitute social engagements that foster community and social participation?
6. To what extent do these programmes improve health status of people living with HIV/AIDS or their adherence to ARV therapy, or encourage people to get tested or disclose their status?

7. To what extent do Cotlands' programmes enable its beneficiaries to be self-sufficient or self-reliant?
8. What challenges remain?

CHAPTER 3: RESEARCH METHODOLOGY

3.1 OVERALL APPROACH

This study was a descriptive, qualitative research, whereby the researcher used a case study method with the intention of uncovering, illustrating and giving a detailed and rich understanding of the impact of HIV/AIDS on the provision of care. The field work was carried over three months. A qualitative approach allowed the researcher to collect words, observe behaviour and analyse them inductively so as to make meaning of the care activities and to describe processes of care (Morrison, 2008). This entailed giving a detailed understanding of the organisation's activities, experiences, responses and challenges in terms of caring for vulnerable children. A qualitative approach was more appropriate for this study because the researcher intended to gain an understanding of care through words and observing activities. In order to achieve this, the researcher used a case study method that was implemented over three months due to the limited scope of the study. Cotlands, an NGO located in Turffontein (Johanesburg), was used for the study because it is an organisation that was established before the HIV/AIDS pandemic and it has gone through many changes to address the challenges of the disease.

3.2 RESEARCH METHODOLOGY

According to Tellis (1997:5), the case method is an "in-depth study of a single organisation which is designed specifically to elicit rich detail about the research site." Critics of the case study method argue that as a result of the small numbers used, the results of the study are not reliable and cannot be generalised (Burawoy, 1998 & Tellis 1997). Some also argue that intense exposure to a case study is inherent of biases and prejudice which also affects the reliability of the study (Tellis, 1995). However, case study methods are used for building on or challenging theoretical assumptions. As a result of the fact that this research intends to explain how care for vulnerable children has changed as a result of HIV/AIDS, the researcher found the case study method most useful because it allows the researcher to give an in-depth description, explanation and understanding of the proceedings around Cotlands care provision.

This study used multiple sources of data (triangulation). These sources are documents, semi-structured interviews, and participant observation.

3.2.1 DOCUMENT ANALYSIS

Data collection for this study started with document analysis. Documents that were analysed included organisational annual reports (2006 to 2010), newsletters (2009 to 2011), brochures and policies (such as the Child Protection Policy 2010, Psychosocial care policy 2010, Access to care policy, policy regarding child abuse within Cotlands, educational policy and Minimum standards) The information the researcher obtained from the documents included the mission and objectives of the organisation, changes in the numbers of children the organisation assists; changes in staff numbers, success stories and challenges facing the organisation in the provision of care; and changes in financial requirements of the organisation due to increased demands in provision of care. These documents generally provided important statistics on the nature, quantity and expected outcomes of various service programmes being implemented by Cotlands. However, most of the information had to be clarified and verified through interviews and is reported upon in the findings.

According to Maxwell (1998:65 *In* Makape, 2008:31) documents are non-reactive, which means that the researcher does not intervene in the context. Over-reliance on one document or only documents as evidence in case studies has been highly criticized (Tellis, 1997). Moreover, most of the documents used represent the interests of Cotlands hence the documents could have some elements of bias. Therefore to reduce potential bias, the documents were used with caution and in conjunction with other methods such as interviews and observation.

3.2.2 SEMI-STRUCTURED INTERVIEWS

Semi-structured interviews were crucial for collecting information that could not be collected using other methods (documents and observations), and for clarifying and verifying some information. Semi-structured interviews allowed the researcher to have a list of questions on fairly specific topics to be covered, contained within an interview schedule or guide. In practice, the questions did not follow the exact sequence of the interview guide, but the researcher ensured that all themes were covered during each interview. The structure was

sufficiently flexible to permit topics to be covered in the order most suited to the interviewee. This also allowed responses to be fully probed and explored. The fact that semi-structured interviews were conducted with a fairly open framework, semi-conversational and two-way communication, made this type of interviewing important for the collection of detailed information on 'care' activities at Cotlands. The interviewing of people involved in different 'care' activities enabled the researcher to gather detailed information needed in order to understand how Cotlands has re-conceptualised care for vulnerable persons in the context of HIV/AIDS. Each interview was approximately one hour.

One of the limitations of semi-structured interviews and its flexibility is that it may lead to an interviewee over-exploring issues that do not answer the researcher's questions (loss of focus). To address this limitation, the researcher kept on redirecting the interview whenever the interviewee lost focus or was not answering the question.

Sampling

The population of this research consisted of the staff members of the Cotlands' national office, caregivers and beneficiaries at the Sanctuary in Turffontein, and the heads and beneficiaries of community-based initiatives located in Soweto. It should be noted that whilst some of the beneficiaries of these initiatives formed part of the population of this study, these were not interviewed; rather they were studied through participant observation.

The organisation is led by one executive director; and a human resources director; national managers including finance, fund development, health, psychosocial and education are located at the Head Office; 22 child and youth care workers at the Sanctuary in Turffontein; 5 child and youth care workers in Turffontein; 2 professional and registered nurses and 3 auxiliary nurses at the hospice; 2 Unit leaders at Cotlands house; 9 community care-givers for the home based care initiatives in Soweto , 2 social workers, 1 nursing manager at the home based care project; 9 counsellors at Chris Hani Barangwanath hospital counselling project and 2 Health facilitators.

For the study, non-probability, specifically utilises purposive sampling was used for interviews. This was done by targeting respondents who had knowledge and/or experience relevant to the study and those involved in the management of the organisation and in the execution of its initiatives. In order to ensure that the researcher obtained diverse information, the sample of the study included employees at different levels of the organisation, such as the managers, the nurses, caregivers and trainers. The participants were sampled according to their availability. Therefore, 18 people were interviewed.

Through interviews, the researcher was able to clarify information obtained from documents and observations. In addition, the above respondents provided insight into different aspects of care-giving which are important for understanding how the organisation has re-conceptualised care. These were from the perspective of the respondent's personal experiences, duties responsibilities and expertise.

3.2.3 PARTICIPANT OBSERVATION

What people document or say is not necessarily what they actually do (Burawoy, 1998). In order to address this issue, the researcher used participant observation in addition to interviews and document analysis. This is in line with ensuring internal consistency of the study. According to Tellis (1997:5) participant observation is a "unique method of collecting data in which the researcher may actually participate in the events being studied."

In order to effectively observe the care provided by Cotlands, the researcher volunteered in the Sanctuary to assist with the children and to be a participant observer in training programmes. Thus as part of the research, the researcher volunteered to assist the care-givers. Every morning for four weeks the researcher would help wash the children, sang and danced with the children during their stimulation programmes and helped to put the babies to sleep during their afternoon nap. To a large extent the researcher was treated as one of the care-givers. One of the memorable experiences of care-giving was when the researcher washed thirteen babies due to the fact that one of the care-givers had taken some children to the hospital for previews. The smiles of the children as the researcher arrived in the morning to bath the children and play

with them, and their cries as the researcher departed could only be captured through voluntary work. There was no other way of the researcher having a feel of what it means to be a care-giver than to be in the shoes of the care-givers. The care-givers were interviewed during their lunch time while the children were sleeping.

Furthermore, it was only through participant observation that the researcher could reveal the feelings and the experiences of Cotlands secondary beneficiaries (primary care-givers) as these beneficiaries are faced with the challenges of the disease and with caring for their infected children. It is through the researcher's experiences as a participant observer or volunteer that she was able to quote some case studies or incidents. Through observing the activities that took place, the researcher was able to further understand what care in the context of HIV/AIDS means.

3.3 METHOD OF DATA ANALYSIS

Data collected from the multiple methods included: transcripts of open-ended interviews, and audio tapes, written observational descriptions of activities, conversations, discussions and people's actions and notes from documents. Themes were drawn from the transcribed audio tapes and written interviews, notes from document analysis and observations. The technique enabled this researcher to compare empirically-based patterns with findings from other studies revealed in the literature review. The researcher was able to build an explanation of the empirical data findings and also challenge some assumptions explained in the literature review based on practice.

Generally, this study made use of developing themes, graphical representation of care practices and the tabulating of information (to draw comparisons between institutional care and CBC) methods.

3.4 ETHICAL ISSUES

According to Babbie and Mouton (2001:520) ethical issues arise out of our interaction with other people and the environment, especially where there is potential for a conflict of interests. In any research, the researcher needs to be aware of the important ethical issues and agreements that prevail in social research (Babbie & Mouton, 2001). These are as follows: voluntary participation, there should be no harm to the participants; ensuring confidentiality and anonymity; there should be no form of deception of the subjects, thereby ensuring that data collection, analysis and reporting of findings adhere to the ethical requirements (Babbie & Mouton, 2001).

In order to ensure voluntary participation by participants, the researcher told the participants that their participation was entirely voluntary. Should they have wished to withdraw during the study, they were free to do so, however, no participant withdrew from the research. The researcher did not apply any pressure or inducement of any kind to force an individual to become a subject of the research. The researcher also ensured that every participant signed a written consent form before they partook in the research. This applied to both the organisation's representatives and to individual participants.

The researcher also ensured that no participants were emotionally or physically harmed. This was done by ensuring that the information asked of participants did not embarrass or endanger the organisation or the participants. My presence affected the children positively as they enjoyed my interaction with them. The children were free to be with me as they were with their care-givers. In addition, no vulnerable people were interviewed for this study.

According to Babbie and Mouton (2001:520), "a respondent may be considered anonymous when the researchers cannot identify a given response with a given respondent." A major limitation of interviews is the fact that it is not possible to ensure anonymity due to their face to face nature (Babbie & Mouton, 2001). Nevertheless, no real names were used in the study. In reporting the findings, participants were identified as Partcipant 2, 3, 4, and so on. According to Babbie and Mouton (2001), with confidentiality the researcher is able to identify a given

person's response but essentially promises not to do so publicly. In adherence to this, this researcher assured the organisation that this project will be used only for academic purposes, and that the media will not have access to it. In addition, the name of the organisation 'Cotlands' has been used with written permission from the organisation. Even though no real names were used for the study, unintended consequence of the description of activities provided in certain Cotlands' programmes is that participants might easily be identified.

According to the ethical requirements, there should be no deception of the respondents. Therefore, the researcher ensured that the participants clearly understood the aims, methods, anticipated benefits and potential hazards of the research,who will have access to the research report and how the findings were to be reported before they consented. To cover this, before the interview, an information sheet was given to participants who were interviewed and to people observed in CBC. However, the children were too young to understand; hence the researcher had to approach them as part of the care-givers (volunteers).

One of the disadvantages of participant observation is that participants can alter behaviour as a result of the Hawthorne effect. To limit this, disclosure to participants was intended to be done immediately after each training session and at the end of volunteering. However, this was not possible because the researcher was introduced to everyone in the organisation as a researcher as she was taken around the organisation. This could have impacted negatively on the research because participants could have altered their behaviour.

When reporting the results the researcher ensured that there was an accurate representation of what the researcher read from Cotlands' documents, observed and was told. Copies of the report will be given to Cotlands; submitted to my supervisors and examiners and lodged with the University of the Witwatersrand for public access.

At the conclusion of the research, any information that reveals the identity of the organisation and participants (such as the raw interview data) will be stored in a safe place.

3.5 LIMITATIONS OF THE STUDY

Whilst the use of multiple sources of information to collect data served to ensure the reliability of the case study, more time could have enhanced the quality of the findings. For example, for participant observation to yield the required results, more time was needed to observe the activities at the community-based care and residential care. Even though observations were used, limited information was obtained. Therefore, time was one of the limiting factors of the study.

In addition, language was another limiting factor. During the interviews, whilst it was clear that the care-givers could understand English and that they understood the questions posed to them, most care-givers found it difficult to answer in English. To deal with the problem, group interviews were held during their lunch time. During the interviews, care-givers could express themselves in their mother tongue and others would translate. Moreover, the researcher realised that the care-givers felt at ease being interviewed in groups and giving answers in their vernacular language. However, when the care-givers spoke their language, the researcher had to wait for someone to translate. This made the researcher feel detached, to some extent, from the proceedings. As it was not possible to have an exact translation, some of what the participants said and their intention may have been lost in translation or in rephrasing. This could have impacted on the accuracy of the findings. In addition, the capacity of participants to influence each other's views (peer pressure) resulting from group interviews could also have negatively impacted on the answers provided. Group interviews also impacted on confidentiality agreements as participants could easily identify who said what.

The researcher could only record interviews held with the management because they felt more comfortable being recorded and had a lot more information to offer which would have been difficult to accurately capture without a recording. Most participants within the lower level of the organisation did not feel comfortable being recorded. Therefore, in accordance with ethics, the researcher did not record the interviews where participants were not comfortable. The researcher's failure to record some of the interviews could also have impacted on the accuracy of the data collected. However, the researcher did whatever possible to write down all the

answers that were provided during the interviews. In addition, the researcher transcribed all the information soon after the interviews.

CHAPTER 4: COTLANDS MODIFIES 'CARE' IN THE CONTEXT OF HIV/AIDS

From the time Cotlands was established in 1936, its primary purpose has been to care for vulnerable people (mainly children). Unable to turn away from the suffering of children in the context of HIV/AIDS, Cotlands is one of the organisations that has been able to modify their care strategies so as to meet the needs and demands of care. Hence, the organisation has been found important for this study which aimed at investigating how 'care' is re-conceptualised by the South African non- governmental organisation in the context of HIV/AIDS.

To answer this question, this chapter seeks to present the empirical findings of the study. A rich set of data including Cotlands' policies, activities and initiatives was collected through document analysis, interviews, participant observations and voluntary work. Presentation of the findings starts with an overview of the organisation, followed by an analysis of who needs care in the context of HIV/AIDS. It is followed by findings on how Cotlands defines 'care'. This includes Cotlands' type of care, how care for HIV positive children differs from those who are negative and changes in staff recruitment, that include the introduction of a multidisciplinary team. Finally there is an analysis of Cotlands' forms of care including residential care (Hospice, Sanctuary, and Cotlands house), community-based care (home-based care, Chris Hani Barangwanath counselling project, Cotlands HIV project and foster care).

4.1 THE HISTORY AND OVERVIEW OF COTLANDS

After having cared for children in her home, Matron Dorothy Pearl Reece founded Cotlands in 1936 to care for unmarried mothers and their infants. 1n 1942 it closed down after failing to meet the operational requirement of the Public Health Department. In the same year, 4000 pounds was raised for the organisation to make the required alterations and Cotlands became a registered charitable organisation (Cotlands, 2011). In 1953 a sanctuary was opened and the organisation started to care also for abused, abandoned, orphaned and terminally-ill children from birth to 14 years of age (Cotlands, 1996). In the 1990's, "Cotlands identified the urgent need to care for children directly impacted by HIV/AIDS" (Cotlands, 1996:3).

Seventy five years after its establishment Cotlands has expanded enormously. It has programmes and initiatives in Gauteng, Western Cape, KwaZulu-Natal, Mpumalanga and its Head-Office in Johannesburg (Cotlands, 2009).

In Gauteng, apart from Cotlands having its head office, hospice, sanctuary and Cotlands house (institutional care) in Turffontein Johannesburg, most of its CBC initiatives are located in Soweto, Alexandra and Thembisa. This research was conducted at residential care in Turffontein and CBC initiatives in Soweto. The fact that most of Cotlands' CBC initiatives are in Soweto made this site important for this study.

Before delving into the findings, it is important to give an overview of Cotlands initiatives and programmes. A detailed explanation of each of the programmes is given in section 4.5. However, it is very important first to give a brief overview because reference to some of these programmes is made from the beginning of this chapter. As a result of the fact that residential care in the literature review is referred to as institutional care, for consistency, the same name will be retained for the most part of the findings section, despite the fact that Cotlands refers to its institutional care as 'residential care.'

Cotlands programme initiatives are divided into three categories, firstly; there is ***residential care*** which comprises traditional institutional programmes such as sanctuaries, places of safety and hospices. It offers care to "abandoned, abused, orphaned and HIV positive children until they can be reunited with their families, or until suitable community placements can be arranged" (Cotlands, 2008:17). The sanctuary caters for a maximum of forty-two children ranging from birth to 14 years old. These are children who have been abandoned, abused, neglected and/or orphaned HIV positive or HIV negative. There are also children whose parents are unfit, either temporarily or permanently. Fostering and adoptions are made from here or the children are sent to other children's homes that care for children who are above 14 years (Cotlands, 2011).The hospice cares for a maximum of eighteen children up to the age of six who are mainly terminally ill with AIDS and other chronic diseases. It provides specialised paediatric palliative care twenty-four hours a day. In addition it provides medical treatment for

children with opportunistic infections who are not yet at the "end stage" (Cotlands, 2009). Cotlands house is a family-like model where children between 6 and 14 years are cared for. The family-like model accommodates 10 children with no other alternative care.

Secondly, there is an ***Outreach or community based care (CBC) programme*** where HIV positive children are assisted together with their families in home based care (HBC); and foster care programme where mature women are recruited and paid to care for HIV/AIDS positive children in their homes (Cotlands, 2009). Chris Hani Barangwanath Hospital counselling project provides counselling to HIV positive mothers and adults. They also provide services to those who are not necessarily positive but are willing to test for HIV (Cotlands, 2010). Soweto Community Centre provides services that include support groups, capacity-building activities such as gardening, beading and sewing. In addition, community workers who could be volunteers or paid by Cotlands visit Cotlands clients once or twice a week or more frequently if there is a problem. The care workers attend to the clients' immediate problems, record progress and report to the managers, nurses or relevant people to assist the clients.

Thirdly, there are the ***Training and capacity-building programmes*** which comprise initiatives aimed at giving people knowledge, skills and empowerment (Cotlands, 2009), these are for Cotlands employees and primary care-givers in the CBC, and range from three-hour workshops to five-day courses, on HIV/AIDS awareness and how to work with and care for the infected and affected. Courses and workshops are aimed at schools, care-givers, parents and learners, people living with HIV/AIDS, as well as community workers or HBC care-givers (Cotlands, 2006).

The fact that the chosen organisation was founded before the emergence of HIV/AIDS and is known for its remarkable contribution towards management of the disease by caring for the affected people, provides a platform from which the researcher was able to make reference to the nature of care and care-giving practices of Cotlands in the absence of the epidemic. The past and the present knowledge of care practices enabled the researcher to explain how Cotlands has reconceptualised care in the context of HIV/AIDS. The researcher was able to investigate how

Cotlands' goals, objectives, policies models of care and initiatives have changed to accommodate the demands of caring for people made vulnerable by HIV/AIDS.

4.2 WHO NEEDS CARE IN THE CONTEXT OF HIV/AIDS?

In order to have a comprehensive understanding of how 'care' has been reconceptualised by Cotlands, it is of utmost importance to have an understanding of who needs care in the context of HIV/AIDS.

For this study Gillespie *et al.,*'s (2005) categorisation (see page 44 for complete details) of vulnerable children was found comprehensive enough to capture the different and major aspects of the impact of HIV/AIDS on children. These aspects of child vulnerability which include being orphaned children living with incapacitated or ill parents due to HIV/AIDS, HIV positive children, HIV positive children living in dire poverty, and children from child-headed families. According to participant 18 the organisation uses the standard definition and categorisation of vulnerable children which is provided by World Health Organisation. In this regard, a vulnerable child is defined as: "A child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance which prevents the fulfilment of his or her rights" (Policy Framework for Orphans and Vulnerable Children, 2003:1).

The above definition is not restricted to HIV/AIDS but to any situation or condition that puts a child's life at risk. This is because Cotlands does not only focus on caring for children made vulnerable by HIV/AIDS. Consequently, the organisation's categorisation of vulnerable children is diverse as specified below:

- Chronically and/ or terminally ill children
- Orphaned children
- Children with physical disabilities and incurable diseases
- Children infected and affected by HIV/AIDS
- Children from dysfunctional families
- Children in homes headed by other children
- Children in poor households and communities

- Children living and working on the streets (Participant 18)

The diversity shown in Cotlands' categorisation differs from Gillespie *et al.*'s (2005) categorisation which focused strictly on children made vulnerable by HIV/AIDS. Hence, by only grouping children rendered vulnerable by HIV/AIDS, Gillespie et al. (2005) gave a more comprehensive classification in the context of the disease as compared to Cotlands. On the other hand, Cotlands groups all children made vulnerable by the disease as 'children infected and affected by HIV/AIDS.' Whilst this lacks specificity, one can also argue that grouping the children as 'children infected and affected by HIV/AIDS' is most effective because it prevents a potential risk of excluding a certain group that may be considered as important. Hence, from the terms 'infected and affected' one can easily infer that all aspects of a child's vulnerability are included. Whilst the researcher considers Cotlands' categorisation as inclusive of all aspects of a child's vulnerability, Gillespie *et al.*'s (2005) categorisation gives more meaning to the concept of vulnerability in the context of the disease.

Above all other considerations, the establishment of Cotlands was not set up to address the problem of HIV/AIDS exclusively. It caters, in addition, for the overall spectrum of orphans and disadvantaged families, and it covers a broader scope than that described by Gillespie *et al.* (2005). Regardless of the differences in categorisation, Cotlands and Gillespie *et al.* appear to have a similar understanding of child vulnerability in the context of HIV/AIDS.

The exact number of children impacted by the disease, other than those who are positive, is not known, but participant 18, stated that most children in Cotlands' residential care have been impacted by the disease (mainly orphaned). In residential care there are twenty-four positive, twenty-eight negative and seven are not yet tested (Participant 15). The figures show that about 46% of children whose status is known are HIV positive. In addition, all two hundred and nine primary beneficiaries in CBC are HIV positive (Cotlands, 2010). These figures reveal that even though Cotlands' categorisation is diversified, most children under its care have been rendered vulnerable by HIV/AIDS.

Another point that sheds light on those who need care in the context of HIV/AIDS is revealed in Cotlands mission, which states that it aims:

> "to provide exceptional models of care to **children** and their **families** by empowering them to improve their quality of life through specialised interventions and sustainability projects" (Cotlands, 2008:3).

After the introduction of community-based care, especially home-based care, in 1999 the organisation made a radical movement from merely focusing on a child to the inclusion of the primary care-giver as a secondary beneficiary. The inclusion of the secondary beneficiary who is an adult, as a Cotlands client, shows an acknowledgement that HIV/AIDS has affected people of all ages. Gillespie *et al*.. 's categorisation of vulnerable people is also confirmed by the fact that Cotlands is extending its care to families. They both confirm, in a way, that family background plays a major role in the vulnerability of a child. Therefore, in order to care for the child effectively, the family has to be assisted. However, in 2011 Cotlands changed its mission (obtained from Cotlands web page) to cater only for young children:

> Cotlands cares for young children in need by providing psychosocial, educational and healthcare services through residential and community-based programmes (Cotlands, 2011).

According to participant 18, the previous approach had been misleading to people. It did not make it explicitly clear that the primary focus of Cotlands was to care for children. The new mission has been implemented in an attempt to make this clear. However, whilst the new mission states that the organisation cares for young children, in practice the organisation continues to give assistance to primary care-givers as secondary beneficiaries.

Based on the above findings, even if the practice differs from the principles, Cotlands has acknowledged that both children and adults need care in the context of the disease. Having illustrated who needs care in the context of HIV/AIDS, the next section discusses the kind of care that is needed and who provides the care**.**

4. 3 COTLANDS REDEFINES 'CARE' IN THE CONTEXT HIV/AIDS

Care was defined for this study as involving activities that are productive such as child-raising, providing the child or adult with food, clothing, shelter, education, and/or finances, medical treatment, nursing the sick child or adult (Boon *et al.*, 2009). These activities cover medical, social and psychological needs provided by either formal (mainly paid) or informal (mainly unpaid) care-givers (Boon *et al.*, 2009).

One of the participants was able to give the following comprehensive narration of events, which was found to be important as it reflects the changes to the conceptualisation of care:

> "For the first **20 – 30 years**, the organisation was 'staffed' by **white housewives** who volunteered their time to provide **basic care** for the children. In the late **60's and 70's** a **domestic helper** was brought in to cope with the cleaning of the facility and attending to the children after hours. By the **80's**the country's economy generally required double income in most households and the housewives went to work which resulted in more and more **fulltime care** being employed. The care-givers employed were generally **uneducated, unqualified black women** who carried out domestic duties and continued to provide **basic care** for the children at Cotlands. From the mid **90's** when the **AIDS hospice opened, nursing staff** were required and the face of **childcare** began to change to accommodate the **development** and **health** of HIV positive children in addition to their **psychosocial** and **educational** needs. The field of childcare required **qualified** and **professional care** to provide **exceptional care** to all the children and this expanded into community care. Recruitment now focuses more on **professional people** who are interested in developing the **community** by visiting clients in their homes, offering health advice, assisting in the care of the children and managing general affairs" (Participant 16).

The above narration of events can be used to illustrate the changes, that is, the types of care provided, and the people providing the care (staff recruitment) and the expansion of care into the communities. Each of these changes is explained in the next section.

4.3.1 CHANGES TO THE TYPES OF CARE PROVIDED

Before the 1990s, when Cotlands started feeling the serious impact of HIV/AIDS, the organisation cared for mainly abandoned, orphaned and terminally ill children (Participant 5). These children were mainly provided with basic care which meant catering for their physical needs**.** This included providing "food, drinks, appropriate clothing, adequate personal hygiene, health, including medical and dental care; and safety needs including protection from harm and safety from injury" (Participant 4). In those years, most children who were admitted did not have major health conditions or chronic illnesses that needed special attention. Participant 16 stated that there were very few children with disabilities and special medical conditions such as epilepsy, cerebral palsy and visually impaired. No formal clinical care was provided on a chronic basis on the premises of Cotlands. By providing for only the physical needs of the children, Cotlands lacked a future vision for the children they cared for.

In the 1990's, however, the challenges and impacts of HIV/AIDS started taking their toll on Cotlands. Participant 18 said "we realised that a lot of the sick children [suffering from diarrhoea] who were brought in were not responding to treatment. After getting them tested, we learned most of these children were HIV positive." Hence, one of the most prominent changes with regards to the concept of 'care' that emerged from the interviews was the introduction of other types/components of care so as to offer 'holistic care'. This is supported by statements such as

> "Cotlands changed focus radically sixteen years ago when it opened the hospice and it introduced the concept of 'holistic care" (Participant 18).

> "The essence of holistic care was introduced in the mid-1990's to save the children"(Participant 6).

> "In a desperate attempt to save the children from dying, Cotlands improved its care services. We now provide total active care to the children…it is care for the body, mind and spirit which is offered through a multidisciplinary team" (Participant 3).

Most participants reflected that the concept of holistic care was introduced as an attempt to save the children from dying from HIV/AIDS. Cotlands defines 'holistic care' as the provision of health, psychosocial, and educational needs of vulnerable children. Cotlands' development from the provision of physical care to holistic care is a remarkable one because the organisation is not only ensuring that the children survive but that they become productive adults. The introduction of holistic care shows an attempt by Cotlands to maintain social reproduction. For this study, social reproduction is defined "in part as the provision of material or social practices which are important for people to maintain life on a daily basis or inter-generationally" (Brenner & Laslett, 1989, *In* Makape, 2008:22).

Even though the introduction of holistic care was a remarkable one, the fact that it was initially limited to institutional care meant that Cotlands did not take care of the source of vulnerability by extending care to the communities. This could have left them exposed to receiving higher numbers of infected children.

From the definition provided by the participants, Cotlands' holistic care is supported by three pillars which are health, education and psychosocial care. Each of these components of care is elaborated on below.

Cotlands' three pillars of care

Literature has identified seven types of care which are essential for meeting the needs of children rendered vulnerable by HIV/AIDS. These include clinical care, end-of-life and bereavement care, psychological care, spiritual care, social care and economic care (Van Dyk, 2008). As stated earlier, Cotlands' re-conceptualised care, that is, holistic care is supported by three 'pillars' which include health, educational and psychosocial care. The organisation classifies spiritual, bereavement, social, psychological and economic care in a broad concept of psychosocial care.

Health/clinical care

Literature regards clinical care as care that is generally provided by medical professionals including nurses, doctors, physiotherapists, midwives, clinical officers, community and volunteer health workers, traditional healers and other physicians (Van Dyk, 2008). Clinical or health care is a very important component for every individual's survival, performance, proper growth and development. As a survival need, Max-Neef (*In* Van Dyk, 2008) argues that it is constant across cultures and at all times; what varies over time and between cultures is the way these needs are satisfied. Confirming Max-Neef's arguments, before the existence of HIV/AIDS, Cotlands ensured that children were provided with clinical care when needed, even if it meant taking the children to the hospitals or clinics. However, one of the more conspicuous impacts of HIV/AIDS is how clinical needs are satisfied. Modifications have taken place with regard to meeting health/clinical care and the health needs of the children. Four important clinical interventions: infection control, provision of palliative care, introduction of ARVs and nutritional interventions were observed.

In the early 1990's, South African people and organisations had no clear knowledge of the causes of HIV, how it could be prevented or how to care for the infected (Beard *et al.,* 2002; Avert, 2011). As a result a lot of actions and interventions were still being researched and some were a matter of trial and error. One of the measures put in place to improve care is infection control. Literature shows the importance of infection control by stating that children who are HIV positive are more prone to infectious and opportunistic diseases because of their suppressed immune system (Joint United Nations Programme on HIV/AIDS, 2010: 22). Therefore, as stated by Participant 4 "the environment had to be kept as clean as possible. There was an increasing use of disinfectants, antiseptic soaps and gloves" (Participant, 4).

One of the first positive things observed was that the Cotlands' environment, including where the children played and slept, was immaculate and the children were kept clean. Care-givers and volunteers were required to wear gloves when bathing all the children and whenever changing the children's diapers. Participant 2 explained that emphasis was put on wearing gloves and on disposing of the gloves once they have been used on a child. This was done to protect the care-givers from infections and also to prevent the spread of the infection to other

children in cases where the children have open wounds or a rash. At Cotlands CBC, there is also emphasis on cleanliness and infection control so as to prevent opportunistic diseases. One of the participants explained "Primary care-givers are educated on the importance of controlling infection and how to use disinfectants. We tell them to wash their hands after using toilets, changing their children and before eating or feeding their children. We also teach them [on] how to control the spread of TB, such as holding their mouths when coughing and opening windows when they are in an enclosed place such as taxis or their homes" (Participant 11). This measure by Cotlands can be regarded as a prevention strategy.

Another prominent change to the provision of care was the recruitment of professional nurses to provide the children with twenty-four hour service. For the first time, health care was provided at the premises of Cotlands. The role of nurses is to monitor and attend to the health issues of all children irrespective of their HIV status and to provide palliative care to chronically ill children. This included immunizing the children, administering medication when the children are sick, reporting any major conditions and lack of health improvements for further intervention at the hospitals. Even though provision of medical care at the premises of Cotlands is an intervention that came about as a result of HIV/AIDS, this medical care is provided to all the children in Cotlands residential care irrespective of whether they were rendered vulnerable by HIV/AIDS or not.

One of the characteristics of HIV/AIDS is that it has no cure yet found. However, ARVs are drugs that can slow down the progress of HIV and thus slow down the damage to the immune system and prolong the lives of people with HIV/AIDS (Maritz, 2002; Van Dyk, 2008). The introduction of ARVs was a critical change to care provided by Cotlands. Once ARVs were proven to be effective in saving the children's lives, Participant 18 stated "We were amongst the first organisations to rollout ARVs to our children. The results were tremendous as the death rate decreased".

One of the greatest and increasingly cited achievements is the decrease in the death rate due to the introduction of ARVs. The effectiveness of ARVs was proven beyond doubt by the case study of Cotlands. According to the organisation's annual reports, a year before the roll out of

"ARVs in 2002, 82 children died in the 18-bed in patient unit. In 2002, the death rate reduced to 52; 9 between 2005 and 2006; only 1 between 2007 and 2008, 2 between 2008 and 2009; 1 between 2009 and 2010" (Cotlands, 2010:30). According to participant 5 seeing the children recover after the rollout of ARVs is one of Cotlands' greatest achievements.

In the institutional care, the ARVs are administered by Cotlands nurses who also monitor the children's progress. Children who would have failed to respond to ARVs are referred to Chris Hani Baragwaneth hospital for further intervention. Emphasis is put on the nurse ensuring that the children adhere to ART. Therefore, all the nurses are required to keep records of all the times they administer ARVs to the children. This is important for record keeping and for future reference. The fact that the nurses are contractually obliged to keep records of a child's ARVs is strength of institutional care which ensures that children adhere to the treatment.

As a result of the fact that all primary beneficiaries in Cotlands HBC are HIV positive, Cotlands ensures that all the children are put on ARVs if they need to be. For this to be possible, care workers and social workers help identify the children and the nurses check the children's CD4 counts. The care workers also check for the children's hospital appointments and ensure that the primary care-givers take the children for the appointments. Participant 11 also stated that it is very important that the care workers check for ARVs compliance/adherence. To do so, the care workers count the pills every visit and check if the child's health is improving.

Despite the fact that Cotlands has an extensive ART programme which ensures strict adherence to the treatment amongst all children taking ARVs, some children become resistant to the medication. In South Africa there are three types of ARVs. They are regime 1, 2 and 3. In the worst cases, children become resistant to all three regimes. The organisation then has to get regime 4 for these children from the United States of America because it is not available in South Africa.

In the communities, in some cases, adherence to ARVs is a challenge for reasons that are discussed in chapter 5. The nurses at the local clinics refer non-compliance of children to HBC.

To address the problem referred to them, Cotlands care workers do home visits and write reports about what they have found out regarding the causes of non-compliance. Participant 11 gave an example of a child who may be staying with an uneducated and uninformed grandmother after the death of a parent. The grandmother is educated on how to administer the ARVs, treat minor illnesses, and how to monitor the child's health.

Another health intervention introduced by Cotlands to address one of the challenges of HIV/AIDS is with regards to the kind of nutrition the children receive. Literature has revealed that children living with HIV and AIDS have increased energy needs compared to uninfected children (UNICEF, 2009). Their "energy needs increase by 10% in asymptomatic children and between 50% and 100% in symptomatic children" (UNICEF, 2009:21) and adequate nutrition is regarded as being needed to optimise the benefits of antiretroviral drugs (ARVs) (Van Dyk, 2008). Therefore, with the help of a nutritional advisor, Cotlands ensures that the children are provided with balanced meals.

In relation to ensuring that the children have adequate nutrition, it was fascinating to observe how often the children in Cotlands residential were fed. The children's feeding times were as follows. At 7:00 am the children would drink milk and cereal/porridge, 10:00 am the babies below 2 years milk whilst the older ones would drink tea or juice and bread, 11: 30 am they would eat lunch (e.g. minced meat, mashed butternut, sweet potatoes, and a little bit of rice or pap). Then they would go to sleep. At 3:00 pm they would eat fruit, yoghurt or drink juice or milk, at 4:30 pm they would eat supper (which is similar to lunch) 7:00 pm they would drink milk and older children would have tea and bread or any similar pastry. At 7:30 pm the children go to bed. Based on the above feeding times, there is no doubt that the children were provided with adequate energy needs which is most important for those on ARVs. The argument provided by one of the nurses and care-giver for feeding the children frequently was that children on ARVs need the food to ensure effective functioning of ARVs. This point is supported by UNICEF (2008:19) who argue that "nutrition is important for the provision of ART to achieve the full benefits." Even though the nutritional intervention was introduced to meet the nutritional needs of children who are HIV positive, all children in the institution

receive the same food, except in cases where a child has specific nutritional requirements (such as those with kwashiorkor).

The organisation also ensures that the nutritional needs of the children in the CBC are met. According to Participant 11 "primary caregivers for children in Cotlands home- based care are trained on how to prepare nutritious meals on low budgets. They are also educated on the importance of giving a child on ARVs adequate nutrients." Participant 11 argued that, the fact that the people being helped are poor does not mean that they cannot have balanced meals. According to the participant, the problem is that the people do not know how to use limited resources to come up with a nutritional meal. Therefore, Cotlands teaches them and provides them with the information. The primary care-givers are also helped to make their own food gardens so that they can be self-reliant and empowered. The above points by Participant 11 confirm arguments by Max-Neef (1991)that care is constant, and what differs is how it is satisfied. In CBC, families are taught to satisfy nutritional needs using limited resources.

In addition, community therapeutic care (CTC) is an intervention established by that addresses the nutritional needs of children in the communities. The introduction of CTC for children who are HIV positive is a crucial change to the conceptualisation of care. "CTC is a community-based approach for managing large numbers of acutely malnourished people that is gaining attention as a viable alternative to the traditional therapeutic feeding centres (TFCs)" (Khala & Collins, 2005:6). In practice, Cotlands care workers, during their home visits, check for any nutritional problems. Furthermore, the Cotlands counsellors at Chris Hani Barangwanath counselling project, identify children who are HIV positive with nutritional problems, who are then referred to CBC for intervention. Participant 11 explained "We check the child's weight. If the child is under-weight we give nutritional advice. We refer them to health information education (HIE). We also refer them to a dietician at the hospitals. We give them food parcels every month [this contains pap, nutritional mealie meal porridge]."

The involvement of families in the improvement of their health was found to be an essential element in ensuring the sustainability of the services offered by Cotlands.

Psychosocial care

In some instances some researchers view psychological and social care separately, whilst others view the terms jointly to form 'psychosocial care'. Whether the terms are viewed separately or jointly, there is agreement by most authors that psychological and social care is very important for vulnerable children in the context of HIV/AIDS. This point is echoed by Cotlands, hence the organisation's inclusion of psychosocial care in its 'holistic care.' as stated earlier. Also mentioned earlier was the fact that in the mid-1990s most children brought into Cotlands were HIV positive. Prior to the introduction of ARVs, care for these HIV positive children mainly entailed the provision of physical needs such as medicine, food, clothing and so on. Other than that, care-givers stated, in the words of participants 4, that "the children were too sick to go out. They spent most of their time in bed" .

The above statements show that the medical condition of the children, in the absence of ARVS, hardly allowed the organisation to provide effective psychosocial care to the children. Adding to the above statements, others also said at that time, "Cotlands witnessed an average of hundred deaths per year and it was like working in a mortuary" (Participant 1). In this context, it was only reasonable that Cotlands' psychosocial care mainly focused on end-of-life and bereavement care for parents or relatives who would have lost their children to the disease. This care is considered as mitigation as it is aimed at reducing the impact of the pain of losing a child to those grieving. As stated by Cotlands' professional nurses, the care included counselling parents or relatives to deal with the pain of losing a child and also to help with burial. The fact that the children were often sick and hardly survived made it difficult for Cotlands to provide psychosocial care directly to these children.

The tremendous impact of ARVs on the reduction of the children's death rate as shown previously made it imperative for Cotlands to start offering and putting emphasis on other components of holistic care including psychosocial care. According to UNICEF (2005:5) psychosocial care for children is "deemed important as more and more babies and young children who are HIV-positive now have access to ART and this will prolong their lives and have a profound impact on them." UNICEF (2005; 2008) argues that care that integrates the major types of care (medical, psychosocial and educational) is most required for children living

or affected by HIV/AIDS to survive and to enjoy a productive life and a good quality of life. The latest Cotlands approach is supported in the literature where there is agreement that medical/health/clinical care alone is not sufficient in dealing with the challenges of HIV/AIDS. Therefore to oversee the provision of psychosocial care, Cotlands established a *psychosocial care policy* which ensures that the psychological, educational, statutory, material, cultural, gender and spiritual needs of the children cared for by the organisation are satisfactorily met (Cotlands policy, 2009). This policy applies to all children cared for through Cotlands institutional care and community-based services. It is a policy that is guided by the Children's Act and the regulations regarding the social work profession.

In practice Cotlands psychosocial care includes, firstly, ensuring that the children have as much exposure to the environment outside the institution as possible. Cotlands care for children ranging from 0 to 6 years in its residential care and the activities of these children vary. For example, unlike the babies (0 to 1½ years), children in the boys and girls units (2 to 6 years) are more exposed to the outside environment. For example, almost every weekend, they are taken to zoos, to the malls and community church and school-going children go to community schools. As limited as these activities may be, they reveal Cotlands' effort to ensure that the children's social and psychological needs are met at least to some extent.

Cotlands also tries to prepare a child for change. For example, Participant 8 stated that:

> "If a child will be going to community school the following year, we prepare the child by taking him or her there to see and we also explain to the child what will be happening. This is important for a child who is in an institution who might not be exposed much to the outside environment."

In addition, participant 8 also stated that a child is prepared psychologically and socially before they get fostered. To do so, firstly a memory book is created for the child. In addition the child goes with a favourite toy she/he played with when in the institution. To deal with the social effect, the child is allowed to visit the family that would be fostering him/her and the family members are also highly encouraged to give the child regular visits in the institution. This is

done to enable the child to get used to the family and new environment and for a bond to be created between the child and the adoptive or fostering family. Fostered or adopted children are encouraged to maintain ties with the institution.

The institutional care model has been highly criticised for its inability effectively to meet the psychosocial needs of vulnerable children (Beard *et al.,* 2002; Desmond & Gow, 2001; Boon *et al.,* 2009). Therefore, mechanisms have been put in place that ensure that children have exposure to the outside environment, and spend as little time as possible in the institution. Such measures include allowing children to be taken home by volunteers. However, from the researcher's observation, the volunteers were very few and not all of them took a child home with them. This meant that very few children had the opportunity of being taken outside the institution.

Educational care

The striking difference between types of care, as identified in the literature and Cotlands' components of care is Cotlands' inclusion of education as a separate and important element of care in the context of HIV/AIDS. In some cases, literature assumes 'psychosocial' as inclusive of education. However, there are increasing arguments that children infected with HIV/AIDS are at a "higher risk of neurological insults, developmental delays and lower cognitive scores than those who are negative" (Kvalsvig *et al.,* 2007: vii). To address this problem, education is found to be crucial. In this regard, this component needs to be regarded as a separate entity. The assumption that education is included in psychosocial care increases the chances that this very important element is overshadowed. Based on this argument, Cotlands' re-conceptualised care puts a great deal of emphasis on providing quality education to its children in the institution and ensuring that all the children in its community-based care have access to education. According to the interviewees and the researchers' observation, Cotlands education programmes vary in intensity and in content so as to be age-appropriate.

Cotlands' educational programme puts emphasis on stimulating babies and this involves activities done to optimise a child's mental, sensorial, social and affective development (UNICEF, 2008). The organisations' emphasis on stimulating the children from a very early

age is in line with the recommendations by UNICEF (2008). Stimulation is done to arrest or to reduce developmental delays and to ensure that the babies and those who have been neglected in their formative years are enabled fully to develop, reach and accomplish certain milestones (UNICEF, 2008).

The above points are also supported by Cotlands annual report (2009:9) which states that stimulation helps:

> "…to encourage healthy development and this begins the moment a child is placed in Cotlands' care, with the objective of enhancing a baby's mental, emotional, physical and spiritual wellbeing. Babies from birth to 14 months are included in Cotlands baby gym development programme, while older children take part in activities such as playing outside, listening to stories and playing with age appropriate toys. These simple programmes have helped babies develop according to expected milestones".

In support of the above point Participant 13, stated that stimulation

> "is a holistic programme provided by Cotlands that looks at child development and is aimed at minimising the developmental delays. As a result of the fact that some HIV children have developmental delays, our stimulation programme is a preventative measure. Most brain development happens when a child is between zero and two years, our stimulation programme, provides a way to stimulate neuropath development. Such programmes include baby gyms and outdoor activities. Medication alone does not help to develop into productive adults."

In practice, the babies in the hospice are stimulated by care-givers for an hour every day. As part of the stimulation process Participant 5 stated: "We massage and stretch the children's hands and legs. We also put them on the floor to play with each other and they are given a variety of toys to play with".

From the researchers' observation the children in the hospice were either too young or too sick to do certain activities. Therefore, their stimulation activities were quite limited. On the other hand, children in the sanctuary who are older and/or healthier were exposed to a number of activities. These include singing, dancing, listening to stories, and painting, puzzle building; and outdoor activities such as leap frog and playing on swings. These activities were mainly for children from 18 months to 2 years. It was observed that the children go through this programme for two hours every day except on the weekends.

In home-based care, primary care givers are taught how to stimulate their children. The care workers also help with the baby stimulation on their home visits. In addition, to enable the stimulation programme in the community, an active learning Toy library located in Cotlands community-based centre was also established. The library is stocked with stimulating and educational toys. The essence of the library is to address the educational needs of the children and to create an opportunity for children in HBC to learn, using toys. According to Participant 11 each care worker takes a toy on home visits and plays with the child. They record the child's responses and also the child's development. The essence of this toy library is to stimulate the child and to identify the child's areas of improvement that are referred to relevant people for early intervention. To ensure accountability as the toys available are very limited, only care workers take toys for the children.

Other than the stimulation programme, Cotlands has also established an early childhood development centre (ECD) (preschool) in its residential care for children who are older than two years but are too young to go to school. Participant 11 stated that "ECD provides a holistic programme for the child. It provides nutrition, indoor and outdoor learning opportunity, language development, psychological development, cognitive or intellectual (maths) programmes and social emotional development." The essence of such a comprehensive programme is to offer the children, not only those who are HIV positive, with a solid foundation so that when they enter school they will be prepared. Cotlands would like to ensure that children who are HIV positive do not only survive but also lead a normal life and that they are able to develop to their full potential (Participant 13).

School-going children are assessed and sent to a community school that suits their abilities. Despite efforts by the organisation to lay a solid foundation (in EDC) which ensures that the children are well prepared when they go to school, it is stated that

> "In 2011, out of 11 children at Cotlands house, only 4 will enter mainstream education, 1 will go to Hamlet (a school for intellectually challenged children), 1 will go to Frances Vorwerg (a school for disabled children) and 5 will go to Sparrows Foundation School (a remedial school where the children are attended to in very small classes and they have access to facilities such as speech and occupational therapists). The children at Sparrow are taken to the mainstream when they are ready. Unfortunately, only 1 out of 10 children has been moved to the mainstream" (Participant 13).

She also added that, even the four that will be going into the mainstream in 2011 will require a great deal of help. Participant 13 also expressed the magnitude of the problem by stating that out of 24 children in Cotlands' schooling programme; only 4 are in mainstream education.

School-going children in HBC are also assisted with school difficulties. As indicated by Participant 11, community care workers do school visits so that the child's problems are identified early and given early intervention. "Where serious concerns are identified, assessments are arranged with educational psychologists and the children are referred to specialised schools able to address specific educational needs" (Cotlands, 2010:13)

To assist school-going children in both HBC and residential care with their homework and school difficulties, a remedial programme was started. This programme is run by volunteers in residential care and care workers in community-based care. The programme entails monitoring the children doing homework, addressing any concerns and assisting the children with specific difficulties identified by the children's teachers, or by children themselves.

From the above findings it is clear that the provision of education is regarded as one of the ways in which Cotlands is providing social reproduction. However, high numbers of children failing to go

to mainstream school seems to suggest that the ECD programme, despite all its efforts, has not been able to achieve its aims.

Differences/similarities between needs and care for HIV positive and negative children

For this study, a question was posed as to whether vulnerable children, who are HIV positive, have different/similar needs to those who are negative, and how care for these two categories of children differs and/or is similar. The identification of the specific needs of each category of children is important in understanding how care has changed to meet the different needs of the children.

Theoretically, the distinction between the needs of children who are positive and those who are negative is not clear. Even authors like Loening-Voysey and Wilson (2001) who give a comprehensive list of needs for orphans and vulnerable children, which consists of survival, security, socialisation and self-actualisation needs, failed to separate distinctively the needs of HIV positive children from those who are negative. The list also fails to distinguish between the needs of vulnerable children in the context of HIV/AIDS from those of children who are not vulnerable. However, recent studies identified two main differences between the needs of HIV infected children and those who are not. Firstly, children who are HIV positive require adequate nutrition that will cater for increased energy needs and the effective functioning of ARVs (UNICEF, 2009). Secondly, there is also an argument that children who are HIV positive may need programmes or interventions that can help them to arrest developmental delays which are mainly found in children who are positive. Participants were asked whether the needs for those who are HIV positive differ from those who are negative, and whether care provided is similar or different.

> "We treat them the same…. Children who are positive are treated as normal as other children. The treatment is the same apart from when we gave the children who are positive ARVs…even then, when it is time for ARVs, those who are negative are given water or multivitamins" (Participant 10).

> "We treat the children the same. They all get psychological, educational, spiritual and medical treatment. When all the children get sick, they are all taken to the hospice for recovery… The way we handle diseases is different because those who are positive are at higher risk of getting opportunistic diseases" (Participant 2).

> "The way we handle diseases is different. Amongst children who are HIV positive we have to watch out for opportunistic diseases and get them treated immediately. Children who are HIV positive have to take their medication. We also take the children for regular check-ups. Otherwise we treat them all the same" (Participant 1).

From the above statements, participants revealed that there are no major differences between the needs of HIV positive and negative children. Where there are differences, these are minor differences which are important for the children's biological necessities. There was also an observation that the need to portray 'care' without discrimination resulted in the care-givers contradicting themselves. There seemed to be fears amongst the care-givers that if they said the care given to HIV positive children was different from those who are negative, the participants would be considered as discriminatory. Emphasis was put on providing the same care to the children regardless of HIV status so as to eliminate discrimination, stigma and to treat all children as normally as possible. These are important issues linked to one of the characteristics of the HIV/AIDS, stigma. As mentioned earlier, HIV/AIDS is regarded as the most highly stigmatized disease in history (Gilbert *et al.*, 2010).

To avoid discrimination participant 1 mentioned that all the children are given the same food to avoid any form of perceived discrimination in the organisation. Participant 4 also stated "To reduce, stigma and discrimination, all the children eat at the same time and eat the same food" .

Observation by the researcher also supported the above statement. Volunteers were required to wear gloves when bathing all the children and when changing the children's diapers. That way, participant 2 explained, "no one would question why gloves are used in this regard, HIV/AIDS has necessitated a different way of treating HIV positive children, therefore, the use of gloves

is an example. This has impacted on the nature of care but the attempt is made to apply this different way of treating children in the same way for all children."

The above statements and observations show some of the ways in which Cotlands addresses the issue of discrimination in its provision of care. In addition, a number of policies have been developed to avoid discrimination and to ensure fair treatment of every child regardless of gender or medical condition. These policies include access to care and policy regarding child abuse within Cotlands systems(Cotlands, 2010). Access to a care policy ensures that all children regardless of race, gender, and culture or HIV status have access to services. The policy regarding child abuse within Cotlands systems prohibits all forms of abuse including any form of discrimination (Cotlands, 2010). In addition, employees have undergone numerous training sessions and workshops aimed at enhancing the employees' understanding of HIV and stigma and discrimination, and how to eliminate stigma (Participant 17).

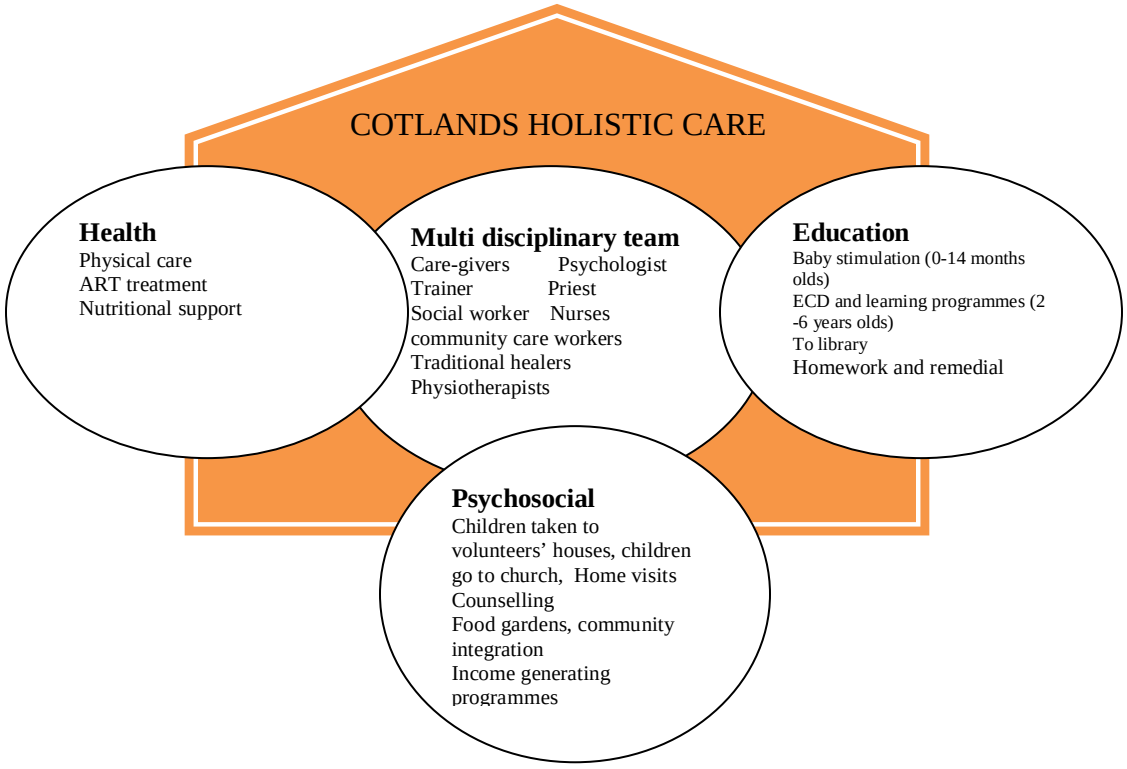
The next section explores changes in staff recruitment as a result of HIV/AIDS. With all the policies, it is easier to control and monitor issues of stigma in residential care.

4.3.2 MULTIDISCIPLINARY TEAM BRINGS DIFFERENT EXPERTISE TO COTLANDS 'CARE'

As depicted in the comprehensive narration provided by participant 16 (in section 4.3), before the impact of HIV/AIDS on the organisation, care was provided by unqualified and uneducated care-givers. The acknowledgement of the fact that children infected and affected by HIV/AIDS have multiple needs, concerns and fears necessitated the introduction of holistic care that tackles all these needs. As a result of the fact that Cotlands could not afford to compromise the standards of provision of care by compromising on the skills of staff members required to offer the services, a challenge that arose was to get the right people with the right knowledge and skills to do the required work. Participant 16 stated that the organisation embarked on a recruitment drive of multidisciplinary professional employees needed to offer the intended services effectively and to meet the needs of the children.

The involvement of a multidisciplinary team is guided by an interdisciplinary team policy which was established to ensure that all beneficiaries' physical, emotional, psychological, educational and spiritual needs are met in accordance with their specific requirements, by a suitably qualified and experienced professional. Psychologists, social workers, care workers, care-givers, counsellors, trainers, nurses, physiotherapists, priests and traditional healers have different expertise and strengths which ensures that the vulnerable children's needs are met. Hence effective provision of the holistic care is highly dependent on the synergy of the skills, knowledge and activities of each team member as depicted in Figure 2.

Figure 2: A diagrammatical representation of Cotlands' care



Effective functioning of this multidisciplinary team is based on commitment of each party together with effective communication and cooperation among the parties.

Participant 16 also stated that the following attitude, knowledge and skills are required for employees to meet the needs of the children and the children's families: Employees need to have a vocational rather than self-enrichment mind set. They need to be people or client oriented. Skills that are required include literacy, numeracy, and resilience, interpersonal and intrapersonal skills.

Knowledge required includes child development and behaviour management, industry trends and progress, HIV/AIDS and ARV treatment, and TB treatment.

In order to ensure that Cotlands employees are equipped with the necessary skills and knowledge that would enable them to offer the required care services, the organisation's trainers and national trainers have had to train the employees. Amongst these programmes are the Minimum Standards, using toys to enhance intellectual and language development, and Curriculum 2011, just to mention a few. The Minimum standards is a training programme offered to Cotlands employees with the aim of providing guidelines on the care required for a vulnerable child, and includes issues such as punishment and rewarding a child (Participant 17). This programme is governed by the South African and international legislation on care. The training on using toys to enhance intellectual and language development of a child is offered by a Cotlands trainer and is aimed at teaching care-givers, teachers in ECD and community workers to be able to identify an appropriate toy that can help address a child's intellectual need or problem (participant 7). In addition, care-givers are required to have a qualification in basic child and youth care, treatment of and medication for minor illnesses. Training and education given to Cotlands employees enhances the quality of care provided, limits error and also ensures that the employees have an understanding of why they have to do things in a certain manner. HIV/AIDS has necessitated reflective and continual adaption of training. As challenges of the disease in terms of caring for the vulnerable, keeps changing, the employees also have to keep up with these developments.

Cotlands is facing intense challenges with regards to employee retention. This is attributed to the fact that the organisation is not able to offer market-related salaries. Therefore, once the employees have acquired the required skills and knowledge they leave for organisations that offer higher salaries. The magnitude of the problem is so great that in 2010 four of nine Cotlands' counsellors at Chris Hani Baragwaneth Hospital resigned which impacted seriously on services offered by the organisation. One of the biggest blows to the CBC project was the resignation of the community-based care manager at the beginning of January 2011. As stated earlier by participant 17, one of the most important attributes needed to provide care for the venerable children in the context of HIV/AIDS is that employees have vocational rather than self-enrichment mind sets. In addition employees need to have a sense of purpose that would enable them to overlook the low salaries and

focus on the differences they would be making to lives of the children. Even if Cotlands cannot pay market-related rates, the organisation has to find ways of offering attractive benefits in order to motivate its employees to stay.

To consolidate the above findings, in the context of HIV/AIDS, Cotlands thrives on offering an integrated, holistic care the success of which highly depends on a synergy, communication and commitment of a multidisciplinary team of employees and stakeholders**.** More than ever, training of employees, so that they are kept up to date with the changes, has become necessary. The next sections illustrate how Cotlands has tried to deal with the problem of accommodating as many children as possible through its re-conceptualisation of care.

4.4 SCALING UP THE 'ISLANDS OF EXCELLENCE': COTLANDS' FORMS OF CARE REDEFINED

Like most NGOs, Cotlands' activities started with a small project. However, it increased in the numbers of children it accommodated in its residential care. The organisation focused on providing high quality or exceptional services to the few children it could accommodate. This, of course, was done at a comparatively high cost.

However, the statistics show 3.3 million children in South Africa have lost at least one parent to HIV/AIDS (USAIDS, 2007). In addition, it is estimated that about 40 000 children get infected with the HI virus every year (Avert, 2011). Concerns emerging from this are: Who bears the burden of caring for these children and what is the feasibility of accommodating these children in countries with limited resources? Therefore, African countries such as South Africa have been urged to make use of its indigenous resources. In this regard, organisations such as Cotlands have been prompted to scale up (expand) its provision of care. According to Reed (2001:5) "scaling-up, i.e. the expansion of NGO's impact has become an important issue." In the absence of scaling-up, "NGO successes remain little more than islands of excellence in a wider economic and institutional environment which is detrimental to the poor" (Reed, 2001:5). By the term 'island of excellence' Reed (2001) is referring to a situation where by an organisation strives for excellence within itself whilst not taking the situation outside it into consideration. In the case of Cotlands, it is when it provides excellent care services to children

particularly in institutional care whilst the millions of vulnerable children outside it continue to suffer.

The establishment of Cotlands' community-based care depicts the beginning of Cotlands' scaling up its provision of care. This is one of the major changes in Cotlands' conceptualisation of care. Even though Cotlands is increasingly making use of community-based care, residential care remains important. Findings of this research identified two means by which Cotlands renders its care. This is through; firstly, residential (institutional) care made up of the hospice, sanctuary and Cotlands house and secondly, community-based care made up of home-based care, Chris Hani Barangwanath counselling project and HIV clinic. Each of these means of care is explored below:

4.4.1 COTLANDS INSTITUTIONAL CARE

Cotlands residential care aim to provide temporary care for sick and/or vulnerable children and is based upon the institutional model of care. Cotlands annual report (2009:16) states that "Cotlands' residential care in Gauteng comprises of three sections: a *hospice* for gravely ill children; a *sanctuary* for children requiring less medical attention; and *Cotlands House*, a home where older and healthier children can be integrated into the community including formal schooling". These children are offered holistic care which includes psychosocial, medical and educational assistance. Each of the forms of care is discussed below.

Hospice

The type of care in a hospice focuses on relieving and preventing the suffering of terminally ill people (Cotlands, 2008). The urgent need to care for children impacted by HIV/AIDS necessitated the establishment of a paediatric AIDS hospice in the 1990s (Cotlands, 2006). Participant 2 stated: "Cotlands hospice was established at the height of HIV/AIDS to offer paediatric palliative care, especially to children who are HIV positive" (Participant 2).

The World Health Organisation defines paediatric palliative care as "an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on

quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement. It is provided for children for whom curative treatment is no longer the main focus of care and may extend over many years" (WHO, 2006:18).

The establishment of the hospice, which was the first of its kind in South Africa, to accommodate HIV positive children, reflects the organisation's ability to change its focus to mirror the changing needs of the children in the society. In this regard, Cotlands annual report (2006: 2) pointed to "care extended through the continuum- from identifying vulnerable children in the community to end-stage hospice care for children dying of AIDS". Therefore, the introduction of the hospice depicts the first change in Cotlands' re-conceptualisation of care as a result of HIV/AIDS.

Even though the hospice was established to assist mainly children who are HIV positive, the organisation has never been a strictly HIV/AIDS organisation (Participant 18). Therefore, admission into the hospice is not restricted to children who are HIV positive as shown from the following categories of children;

- Children between birth and 9 years that are in the end stage of a life threatening disease e.g. AIDS or cancer, are eligible for admission.
- A chronically ill child with very little or no resources, both human and material, to care for him/her at home
- Short term respite care for children living in child-headed or granny-headed households, or where the primary care-giver is very ill (Cotlands, 2010:1).

The above categorisation is based on Cotlands' admissions policy. According to participant 1 the purpose of the hospice is to provide temporary and palliative care, for children who are severely ill. At the hospice the children are given treatment and their response to the medication is strictly monitored by nurses who provide the children with a 24 hour service. Upon recovery, the children are reunited with their parents/relatives or get adopted/fostered (where possible) or moved to the sanctuary if the child is above 18 months.

However, in the absence of so many children getting ill as a result of the effectiveness of ARVs, other than providing palliative care to children, the hospice currently, accommodates abandoned babies on a temporary basis and also serves as a place of safety. Based on observations, most children in the hospice were not ill. Even though the hospice was meant for children who are not well, the introduction of ARVs enables the children to recover quickly and to be moved to the sanctuary or reunited with their parents. Participant 1 stated that all children in residential care (Sanctuary and Cotlands house) who are sick are sent to the hospice for treatment and recovery.

Once again there is no doubt that the introduction of a hospice at the height of HIV/AIDS to give special care to severely ill children was a remarkable one. This is all the more remarkable given the fact that there were, at that time, no ARVs. However, Cotlands participants themselves stated that ARVs have been so effective that they hardly have severely ill children. Even if severely ill children are brought into Cotlands, the effectiveness of ARVs and the quality of care given to the children means that these children quickly recover. Given all this, Cotlands hospice is currently serving a different function as there are very few severely ill children. In addition, the researcher is of a view that keeping the children in the hospice prevents the organisation from 'normalizing care provided for the children'. Therefore, in order to normalize care given to children impacted by HIV/AIDS, Cotlands may have to redesign the hospice into another unit similar to the sanctuary. The organisation will still need a nurse to continue monitoring the children, but she does not necessarily need to be in the hospice.

Sanctuary

The sanctuary is the second component of Cotlands' institutional model of care. The sanctuary which was established in 1953 is an historical unit which remains the heart of Cotlands regardless of the fact that the organisation has had to diversify its models of care (Cotlands, 2006). It is divided into babies, and boys and girls units. It aims at providing 'holistic care' for abused, abandoned, orphaned and HIV positive children until they can be reunited with their families, fostered or adopted (Cotlands, 2008).

The criteria for admitting children into the sanctuary as stated in Cotlands admissions policy is as follows (Cotlands, 2010:1):

- Children should be between the ages of birth and 5 years
- Abandoned, neglected, abused and orphaned children, identified as such by social workers or police officers
- Children on antiretroviral treatment who cannot be discharged to their families due to unfavourable home circumstances
- Children with severe but not life-threatening disabilities who will require life- long care are excluded from sanctuary criteria, and need to be referred to an appropriate care facility such as Little Eden (an organisation that takes care of severely impaired people).

Unlike the hospice, the sanctuary is supposed to care for healthier children. The use of sanctuary to care for vulnerable children is one aspect where Cotlands' mechanism of providing care has not changed in the context of HIV/AIDS. The content of care provided has however changed since the children are provided with holistic care.

Cotlands House

The fact that the children are living longer is a big achievement for Cotlands. However, the difficulty in getting children who are HIV positive fostered or adopted is a major challenge for the organisation which offers temporary care to young children. Generally, Cotlands does not cater for children above 5 years. The children above 5 years are either fostered, or adopted, or returned to their family (if family member are alive). If none of these placements are available a child is sent to organisations such as St Mary and SOS children Villages which are NGOs that care for older children up to the age of 18 years (Participant 18). However, in cases where these organisations are full, Cotlands has to provide an age-appropriate and alternative solution to the hospice and sanctuary. Therefore, one of the major changes that have taken place in the way care is provided is the introduction of Cotlands House.

Established in 2002, Cotlands House represents a family-like model where healthier and older children between 6 and 14 years of age are allowed to be reintegrated into the community where their physical, emotional, social and intellectual (psychosocial) needs can better be met. This is care that enables the children to live and enjoy normal life, develop to their full potential and develop into participating, contributing adults. The family-like model is an imitation of a 'normal' family set up. The children live in two flats in which the wall dividing the two flats was taken down to have boys and girls sides. A total of 10 children stay in the house and all of them are HIV positive.

According to participant 18, "the children are a maximum of two or three to a bed room. …they have their own private bathrooms, they go bath one at a time instead of being all lined up (like in the sanctuary). So, the boys' bathroom is separated from the girls'…It's (Cotlands house) certainly, more age appropriate, they have more responsibilities, like they help with preparing meals and doing dishes."

There is a care-giver who is like a 'mother' to the children even though she works a shift system. The care-giver stays two days in and two days off. Unlike the care-givers at the hospice and sanctuary who work either a day or a night shift, a care-giver lives in with the children for two days before taking another two days off. In total there are 2 mothers. The fact that the care-giver lives in for two days enables the children to be with the same care-giver for longer than those in the sanctuary and hospice. This exposure to the same care-giver for a longer period of time is important for the formation of a meaningful relationship between the care-giver and the children. These relationships are crucial for the developments of children's social skills. The care-givers are there to offer necessary parental guidance through the crucial life-stages of identity formation and socialisation into adulthood of the children (Participant 18). In addition, like in a normal family, the children can invite friends over and play in the garden. Unlike the children in the sanctuary and hospice who go to Cotlands ECD, children in Cotlands house go to school in the neighbouring community. This is important for the children's exposure to conditions outside the institution and for socialisation.

However, as stated by Participant 18

> "it is nowhere near a natural family. The truth is, it is still a care worker who is essentially paid to do the job. As great as she may be, she goes off duty, she goes on leave and a reliever comes in. Whereas in a family, a mother never goes away. The mother is always there, there might be rare occasions that she goes away but she does not take annual leave".

This above statement may indicate a likely disruption to the formation of meaningful relationships and attachments when the care-givers take leave days. Nevertheless, Cotlands house is a great improvement on the hospice and sanctuary in terms of normalising the children's lives, children's social roles and exposure to life outside the institution.

4.4.2 COTLANDS COMMUNITY-BASED CARE

Cotlands' institutional care can evidently accommodate a maximum of 70 children (about 18 in the hospice, 42 in sanctuary and 10 in Cotlands house 3.3 million children have lost both or one parent to HIV/AIDS (USAID, 2007). Some of the children are chronically ill, or are staying with severely ill parents (Flanagan, 2007). In such circumstances, Clark cited in Reed (2008: 4) argues that "only a complacent organisation would be content to continue with the same job in perpetuity when it is self-evident that its contribution is not more than a drop in the ocean, however excellent a drop it may be." From this perspective, findings show that Cotlands had to look for strategies that are cost- effective and can reach to as many people as possible.

Participant 18 supported the above argument when she mentioned

> "We have moved from focusing primarily on residential care to community-based programmes. Residential care can care for about 60 to 70 children at most. Whereas for a third of the cost we can help 300 children in the community. In a country where many, many children are starving to death, [in highly resource- constrained environments] it seems extravagant to extend residential care, which is expensive".

The movement towards CBC reflects another major change in Cotlands' conceptualisation of care. For the first time in the history of the organisation, care for vulnerable children in the

context of HIV/AIDS is no longer limited to residential care. Literature defines CBC as "care that the individual can access nearest to home, which encourages participation by the people, responds to the needs of people, encourages traditional community life and creates responsibilities" (Ncama, 2005:33). Based on the Cotlands Timeline (2011) (attached in Appendix 6), the organisation's movement towards community-based care started as a research project in 1993 when a community centre opened to offer therapeutic services to the communities where people were affected by HIV/AIDS. Hence, poor families with children between 0 to 14 years were provided with food. However, this strategy, which started as a project, was expanded and implemented to form 'Cotlands CBC.'

As stated earlier, CBC comprises three projects. These are: Home-based Care (HBC), Chris Hani Barangwanath hospital counselling project (CHBH) and HIV Clinic project also situated at Barangwanath hospital. The primary purpose of the outreach or community projects is to assist as many children as possible in their homes/communities. The main objective is to provide palliative care to chronically and terminally ill children (mainly those who are HIV positive). The demographics of vulnerable children, lessons learnt from other community programmes and other challenges, made it impossible for Cotlands to assist a vulnerable child in the community without assisting or empowering the primary care-giver. To support this point Cotlands annual report (2010:6) states "on- going change in the demographics of Cotlands beneficiary base, the effects of the global economic crisis and emerging trends from increasingly effective HIV/AIDS trends programmes forced Cotlands to re-evaluate the focus of its service…Cotlands care for vulnerable children has continuously evolved, but the review period has seen a fundamental shift in our organisation's focus- from primary to secondary beneficiaries."

In cases where children being cared for by Cotlands are living in communities, Cotlands supports the carers of the child and anyone else living in the child's house as secondary beneficiaries. Empowerment of secondary beneficiaries is done through training, education and capacity-building programmes, primary care-givers (those who are directly responsible for taking care of a child) are provided with knowledge and skills they require to care for themselves and their children. These programmes reflect Cotlands' efforts to maintain social

reproduction by transferring skills to the broader society that would enable care-givers to care for their children effectively.

Cotlands' strategic shift from solely caring for the primary beneficiaries (only children) to also focusing on the secondary beneficiaries can effectively be explained using Brofenbrenner's systems theory or ecological theory. The systems theory states that a child cannot be understood in isolation from his or her family or environment (Paquette & Ryan, 2002). It implies that an effective intervention that focuses on a child needs to empower the family. In this regard, Cotlands endeavours to assist families to care for their children. The involvement of the family may provide Cotlands with a better understanding of the child's background and basic problems. It also enables Cotlands to deal with the root of the problems rather than dealing with the symptoms. In addition, by involving the family, Cotlands is able to care for a child in his/her natural setting and a child is provided with care by people he/she can understand socially, and psychologically relate to. It should, however, be noted that the involvement of a family, though important, is not the only way a vulnerable child can be taken care of.

A more detailed explanation of each of the components of Cotlands' community-based care programme follows, commencing with the home-based care, followed by CHBH counselling project and the HIV clinic.

Home-based care

In this context, Cotlands' HBC which started in 1999 as a research project initiated by Cotlands on behalf of the National Department of Health was established to care for some of these children in their homes. Families come into the HBC programme through referrals from Cotlands counselling project at Chris Hani Barangwanath hospital and also referrals by other organisation such as social welfare. The child admitted into the programme must be HIV positive, and must come from a poor, child and/or grandparent-headed family. According to Cotlands' annual report (2007:8) "the main aim of the home-based care is to meet the needs of children impacted by HIV/AIDS in their communities and families where resources are limited". It cares for about 300 children.

According to Cotlands annual report (2007:8) the main objective of "home-based care is to help families care for their HIV-positive children at home and support these families with appropriate home care for minor medical problems, assist with hygiene needs such as bathing and household chores". These children are also provided with over-the counter medication such as multivitamins, painkillers, de-worming syrup and disinfectants, material aid (mainly food), assistance with accessing social grants, education (provided with remedial) and accessing and administration of ARVs (Cotlands, 2006). Core to the HBC programme is nutritional projects, assistance with accessing grants, income-generating projects and social groups which are all linked to the provision of psychosocial care.

Following the discussion on adequate nutrition among HIV positive people and the large numbers of children in need of care presented in the literature review, Cotlands' attempted to address this through HBC. Community therapeutic care (CTC) is a home-based approach which could manage a large number of malnourished HIV-positive children and this was established in 1999 (Cotlands, 2006). This was discussed in section 4.3.

In view of the provision of psychosocial care, Cotlands social workers and care workers ensure that all children have birth certificates that can enable them to access government grants. Even though Cotlands does not provide the actual grants but it facilitates access to the grants by assisting with the application process for grants. The organisation's assistance to people in obtaining the grants is a way by which the organisation has included social security and social reproduction in its conceptualisation of care. The grants are given to the primary care-giver. The grants are as follows: foster care grant (R680), child support grant (R240) given to unemployed mothers for their child, dependence grant (R1010) given to sick people who might be HIV positive but when the care-giver's CD4 count goes up, the grant is stopped. Dependency grant is also given to disabled children. One of the challenges facing some South African people with regards to accessing grants is lack of knowledge and when clients do not have the necessary documents. Therefore, Cotlands assists the children to get the necessary information and provides information on the grants to the primary care-givers.

At HBC primary care-givers are involved in income-generating projects such as mosaic work, sewing, beadwork and jumble selling of old clothes obtained from donations. These are aimed at ensuring that the clients are empowered and self-reliant.

Other than the nutritional programme, and income-generating projects, in September 2008 Cotlands' Home-based care programme opened a community centre in Diepkloof, Soweto. This centre is used for support groups of primary care-givers. According to Cotlands (2009: 2):

> "These are women (primary care-givers) of different ages - including grandmothers who care for their orphaned grandchildren. The support groups, attended by some 80 women every week, provide emotional support and empower the women with knowledge and skills to enable them to give quality care to their HIV infected children and grandchildren. Cotlands provides each participant with a cooked meal and a food parcel to take home at each weekly meeting. The centre also houses the programme's income-generating projects - beadwork and a thriving pajama factory".

The establishment of support groups reveals Cotlands' inclusion of social capital in its re-conceptualised care. The intended benefits from the support groups include the encouragement of beneficiaries to disclose their status, to share information and to find creative ways of solving their problems (Participants 15). They are also educated about HIV and sexually transmitted infection (STI) and a great deal of emphasis is put on adherence to ART. It is very important that Cotlands educate its people about HIV/AIDS and adherence to ARVs. However, people in the social groups might be willing to adhere, but the cultural beliefs and stigma in the communities and their families may lead to some people not wanting to get tested or to adhere to ART. Therefore, Cotlands might have to find a way of reaching out to the community rather than merely the individuals.

Moreover, as revealed in chapters 5 and 6 where a detailed evaluation of Cotlands projects is provided, clients hardly make use of services such as the support group and income-generating projects. This may be linked to lack of interest; fear of stigma; or the clients might not have a good understanding of the intended benefits. The implication of the lack of cooperation from

the secondary beneficiaries means that the primary beneficiaries are not able to benefit from the services offered by Cotlands and they may remain vulnerable.

Chris Hani Barangwanath Hospital counselling project and HIV clinic

Chris Hani Barangwanath Hospital is one of the largest hospitals in the southern hemisphere servicing people in Soweto, surrounding communities and people with special conditions who are referred from other hospitals and clinics. Hence, the hospital is recognised as one of the biggest and busiest hospitals. Yet, the hospital is marred by a shortage of doctors, nurses and counsellors. The hospital's professional staff members are overburdened and unable to provide psychosocial services over and above their primary medical responsibilities (Participant, 9). In this context, Cotlands' establishment of a counselling project in 2003 aimed at providing psychosocial support for the care-givers of children living with HIV/AIDS at Chris Hani Barangwanath can be recognised as a strategic move. This is because Cotlands is able to contact the affected people whilst they are outside their community, where no one knows them, hence the exposure to stigma is limited. In addition, it is easier y and more feasible to access vulnerable children, in the context of HIV/AIDS, in the hospitals than it would be for its employees to go door to door. However, the organisation might not be able to assist vulnerable children in the communities who would not have gone to the hospitals.

The implication of Cotlands' strategic move can effectively be explained using the following:

> "If you see a baby drowning you jump in to save it; and if you see the second and a third, you do the same. Soon you are so busy saving drowning babies that you never look up to see that there is someone throwing the babies in the river" (Ellwood 1992 *In* Reed, 2001:26).

Based on the above, by assisting already sick or vulnerable children, Cotlands is not getting to the root cause of the problem. By so doing, Cotlands runs a risk of receiving more children. It is important that Cotlands continues to assist patients at the hospital; however, it has to find ways of getting into the communities to reduce the risk of vulnerability.

At CHBH, counsellors are able to identify a large number of vulnerable children who are either referred to Cotlands residential care or HBC for care and support. According to participant 9, the nurses and doctors are too busy to counsel primary care-givers. Hence the Cotlands' counsellors provide pre- and post-counselling for mothers who bring their sick children to the hospital. During the counselling, the counsellors encourage the mother to open up as much as possible. It is through the counselling that the counsellors are able to identify some special problems that need to be referred to social workers at Cotlands home-based care. The counsellors also offer bereavement counselling for mothers who have lost their children and to children who have lost their parents to HIV/AIDS. In addition, it is at Barangwanath hospital where the counsellors identify children who are abandoned (they could either be HIV positive or negative). These children are referred to Cotlands hospice were the children are cared for temporarily. Abused children are referred to Ntabiseng, an organisation for abused children. Women who have been abused are referred to welfare organisations such as People Opposing Women Abuse.

According to Cotlands annual report (2010: 28) the counselling session is a "therapy or education event where a client receives counselling on the challenges and realities of living with HIV, as well as other illness such as cancer. Therapy often includes stimulation of children in hospital, since a long period of hospitalisation can lead to further developmental delays unless children are regularly afforded physical and/or academic stimulation (such as reading and writing)".

The importance of counselling primary care-givers at CHBH, as cited by participant 9, includes the following: "it relieves the primary care-givers of stress; to help them secure social grants; we are able to identify abused children and children who are in need of home-based care or residential care. In addition, counselling helps the primary care-giver with emotional support. We are also able to educate the care-givers about treatment- the benefits and side effects of ARVs" (Participant 9).

During the interview participant 9 stressed the importance of educating the mothers or primary care-givers about side effects of ARVs. According to the participant, 'if the care-givers are not

educated about the side effects of ARVs, they may stop taking them once they find out on their own" (Participant 9). Hence, Participant 9 found it important to point out the side effects and stress the benefits of taking the medication. Other than educating about ARVs, the counsellors also educate the care-givers about family planning, health education and other diseases such as TB, and STIs. A major emphasis is put on how to prevent the transmission of HIV.

Participant 9 stated that primary care-givers who would have found out their HIV status or the HIV status of their children, and those who would have lost their children to HIV/AIDS need special counselling. According to Participant 9;

> "those who would have lost a child and may not have money to bury him/her need special counselling because the children are given pauper's burial by the government. The fact that they will never be able to identify their child's grave is immensely painful for the care-givers".

Hence, the counsellors help the care-givers to deal with the pain. After counselling the care-givers are also referred to the social workers for extra help. Upon discharge, the mother or primary care-giver is referred to Cotlands HIV Clinic where she can take her child for reviews, ARVs and so on. Clinic defaulters and families are followed up telephonically and via house visits.

The above findings reveal that the care services that Cotlands offer vary from mitigating to preventive where the counsellors educate the care-givers about preventing the spread or contraction of HIV. Hence in a different way, care provided by Cotlands at Barangwanath comprises the essential elements, medication (provision of ARVs), psychosocial (provision of social grants, reference to social support services, bereavement care), and education (health education, family planning, HIV, TB and STIs). The assumption behind counselling a primary care-giver is that "children are better able to cope with their vulnerabilities when their adult care-giver is psychologically healthy and able to provide love and cognitive stimulation" (Richter, Foster & Sherr 2006, *In* Wakhweya *et al.*, 2008). This point is supported by the systems theory explored in the literature review.

Foster care (placement)

As stated in the literature, HIV/AIDS has overwhelmed the traditional models of care and the use of institutional care is largely being discouraged and organisations are forced by the South Africa government and international bodies to keep these to a minimum (Rayneke-Barnard, 2005). A question that rises from this challenge is how else vulnerable children can be accommodated. Cotlands (2008: 6) stated that "as the extended families, foster and adoptive parents recruited though the usual channels are saturated, the organisation was looking into alternative models of community care for HIV positive children who are clinically well and receiving ART" Therefore, Cotlands established a professional foster-care programme. This is a form of community-based care programme where unemployed mature women who are willing to act as parents for two or three children in their own houses are recruited (Cotlands, 2008). The "women receive a foster care grant of about R 650 from the government and Cotlands would add an additional R1000 per month" (Cotlands, 2010: 59).

This new model of CBC was implemented in 2009 and so far 11 children have been discharged into the care of foster families (Cotlands, 2010). This new model has already faced some challenges which include the difficulty in obtaining foster parents. This is because recruitment of foster parents needs serious scrutiny; otherwise the children could fall into the hands of abusive parents who could endanger the already vulnerable children. In addition, regular visits to the families may be needed to ensure that the children are receiving the necessary care and all problems are being addressed as they arise. Very little information is available on this new model of care.

4.5 COTLANDS BUILDS PARTNERSHIPS

A question must be posed as to how NGOs and South Africa can cope in terms of caring for its vulnerable children. How has Cotlands managed to expand its scope in such an under-resourced nation? One of the answers to these questions lies in an organisation's ability to form partnerships. According to Villarreal (2006) creating and maintaining successful HIV/AIDS programmes and financial partnerships that have a real impact are crucial to managing and

fighting the epidemic. Hence, Findings reveal the building of partnerships to be one of key strategies used by Cotlands in order to respond effectively to HIV/AIDS. These partnerships are a major part of Cotlands' social capital and are meant to reinforce an ongoing collaboration in fighting and managing HIV/AIDS among Cotlands, other NGOs, South African government, the private sector and families.

As indicated in one of Cotlands brochures "Cotlands is committed to aligning its programmes as closely as possible with government and global objectives for the welfare and protection of children" (Cotlands, 2010:1). By aligning itself with the government, Cotlands is able to obtain policy guidelines and legislation. In addition, Cotlands obtains about 15% of its budget from the government (Participant 14). The South African government provides grants to underprivileged families and Cotlands assist its beneficiaries to access the benefits. The partnership between the organisation and the South African government is most important for the effective functioning of CBC.

Other than forming partnerships with the government, "Cotlands entered into a health education partnership with the Medical Knowledge Institute- an international non-profitable organisation that establishes learning centres in developing countries to provide healthcare education and information to the general public to promote individual and community health" (Cotlands, 2010:29). Cotlands has also formed partnerships with organisations such as "Project Trust (UK), AIESEC Europe (a youth leadership organisation) and American Field Service (Germany)" (Cotlands, 2010:29). These organisations provide NGOs such as Cotlands with volunteers, hence, Cotlands is able to benefit in terms of man power. Cotlands has also formed partnerships with other NGOs such as SOS Children's Villages and St Mary where some older children in the institutional care are sent for longer term care (Participant 14). Other than this, children who have severe impairments are sent to Little Eden. All these partnerships enable Cotlands to benefit itself from resources it otherwise might not have been able to acquire. The organisation has been able to use the resources to expand its provision of care. In addition, partnerships enable sustainability of Cotlands' projects and also broadening the finances required to care for the vulnerable children.

This chapter has shown the highly commendable services rendered by Cotlands and the utility value of the organisation. It has demonstrated how the organisation has managed to modify its care and expand its models of care so as to deal with the challenges of HIV/AIDS and the scope of vulnerable children.

CHAPTER 5: EXPLANATION AND EVALUATION OF INSTITUTIONAL CARE AND CBC

Cotlands' expansion (scaling up) of mechanisms/models of care is one of the most prominent ways in which care for vulnerable children has been re-conceptualised in the context of HIV/AIDS. This chapter provides a detailed analysis of the practicality of the models and the pros and cons of each model in providing care for a vulnerable child in the context of the disease.

5.1 SCALING UP HEIGHTEN THE MODEL OF CARE DEBATES: INSTITUTIONAL VERSUS CBC

Many studies have documented mainly the positive aspects of CBC and the negative aspects of institutional care. Families and communities have always been the primary place for a child's nurture and growth. Hence, there is an assumption by many writers who advocate CBC that families and communities are always willing and able to give appropriate care to their children as long as they are assisted to do so. As stated by Russel and Schneider (2002:328) "communities are often assumed to be homogenous and unproblematic entities and little is given to the task of mobilising them." These assumptions have led to over-simplification of CBC and its ability to provide care for a vulnerable child. What has not been explored, to a large extent, are the challenges arising from CBC. This study found that, even though communities are homogenous in one sense, they are made up of individuals who may display differing practices, views, norms, beliefs, values and personalities. All these aspects of individual differences may be over-looked when a community is perceived as being homogenous and, as a result, this may contribute to challenges so intense that in some cases they prevent vulnerable children from benefiting from the services provided. In practice CBC is much more complicated than has been depicted by most researchers. The case study of Cotlands shows that the need to scale up has complicated the concept of care and has also heightened the debate around the models of care. Analysis of the practicality of the models of care will start with findings on institutional care followed by CBC

5.1.1 PRACTICALITY OF COTLANDS INSTITUTIONAL CARE- THE 'GOOD' AND THE 'BAD'

Literature has often depicted institutional models as having a seriously negative impact on children's rights, growth and development. The debate around the negative effects of institutional care on vulnerable children existed long before the discovery and the impact of HIV/AIDS. However, the existence of HIV/AIDS and the millions of children rendered vulnerable by HIV/AIDS and in need of care has definitely heightened the debate. Some of the negative effects of institutional care include the 'segregation, discrimination and isolation that institutionalised children often experience; the fact that admission is often based on the needs of parents, not the interests of children; the lack of personal care and stimulation; the lack of opportunities to learn about the roles of adults; the high risk of institutional abuse; the lack of attention to specific psychological needs; and finally, reflecting all of these features, the fact that institutionalised children often experience problems in adjusting to life outside of the institution' (Tofree, 2003:5).

Amongst the above seven points identified by Tofree (2003), participants only reported segregation and discrimination faced by the children. One of the participants reported a case where a school refused to admit children from Cotlands because they are likely to be HIV positive. A report was filed against the school and the children were then admitted. However, there was very little evidence to confidently confirm that the children experience discrimination and segregation.

Other than the negative impact of institutional care identified by Tofree, this study could also confirm the argument made by Tizard and Rees (1976: 76 in Morrison, 2008: 56) that "children brought up in institutions tend to suffer from two disabilities: stunted individuality caused by habitual conformity with institutional rules and delayed emotional growth caused by love starvation." One of the participants said:

> "Too many rules and routines are a disadvantage to the children because the children do not live a normal life with no set of rules and regulations. Children find it difficult to cope

when they are eventually put in an environment with no rules. But the children are too many; they can't live without rules because it would be chaotic" (Participant 1).

According to the participant, children who live in institutions where they are rule-bound and have to follow routines find it difficult to adjust to a flexible environment. Rules are important for imposing discipline on what could potentially be chaos. In addition, routines in an institution are important for organizing and managing the staff and the children. However, there is also a tendency for children to become so used to the routine that they may find it difficult to cope when they leave the institution or get reunited with their parents. The number of routines and regulations which contribute to the unnatural provision of care is something that Cotlands may have little control over if it has to function effectively and have control over things.

One of the most cited disadvantages of institutional care from the literature is the high child to care-giver ratio which prevents the children from getting the one-on-one attention which children need for development. The researcher observed that when one baby in particular was carried frequently, other babies at the baby sanctuary would also want to be carried, hence they would start crying. Furthermore, there were only four care-givers at the baby sanctuary. Consequently, when it was feeding time, a care-giver would only be able to feed one child at a time whilst other children would have to wait their turn. Whilst some children waited patiently, others got anxious and some cried uncontrollably. This highlights the challenges resulting from a high child to care-giver ratio. Participants 2 and 15 stated that the ratio of care-giver to child at Cotlands is normally 4:1. Whilst this ratio is low compared to other South African institutions and families, this ratio is considered high by the researcher given the fact that one care-giver would have to look after 4 **babies**. Even though there are usually volunteers to help, the situation is worsened when one of the care-givers has to take a child to the hospital.

In addition to the above-mentioned criticisms of institutional care, Participant 12 stated that no matter how much the organisation attempts to meet the needs of the children, it can never replace a family. This point can further be illustrated through the researcher's experience below:

On the first day the researcher walked into the girls unit. The children were getting ready to take an afternoon nap after preschool. One of the children, pointed at the researcher and yelled to the other child 'Dipuo, there is your mother.' The little girl, Dipuo (not her real name), looked at the researcher with excitement. The little girl walked toward the researcher and the researcher, smiled and stretched out her hands to reach out to the child. The researcher carried Dipuo and Dipuo asked, 'Are you my mother?' Astonished and not knowing what to say for fear of disappointing the little girl, the researcher, with a smile on her face, responded. 'No, but I have come to play with you.' Dipuo faintly smiled back. Another girl came towards the researcher who was still carrying Dipuo and asked 'Dipuo, is that your mummy?' Dipuo did not respond.

The case above reveals one of the most important needs of children that the institutional care cannot cater for; the need for affiliation or the need to belong to a family. The above example reveals some of the children's expectations of being reunited with their families or being fostered. Cotlands institutional care is aimed at providing temporary care for children (in this case, those with biological parents) who could be placed in the institution for the following reasons: the child could be sick and placed in Cotlands for monitoring and recovery, the child could be exposed to family violence that could endanger his/her life, the parents are abusive, the family has no financial means to care for the child, a child with severely ill parents, or children from teenage parents with no one else to care for them. Under these circumstances the child may be placed in the institution until the situation improves. It is therefore, important for the family to maintain a bond or attachment with the child whilst the child is in the institution. This is also important for the child to know his or her identity. To facilitate this, family members are allowed to visit their children regularly. However, some participants expressed their sadness when they stated that some parents or relatives have never returned to see how these children are doing. Participant 10 showed her concern: 'Some parents or relatives have not appreciated or recognised how important they are to their children'. Participant 1 said that no matter how much emphasis is put on the importance of parents visiting their children, some do not visit.

She stated:

> "Parents do not visit their children. It is depressing. When a parent does not visit, a social worker visits the parents or relatives to check what the problem could be. If the parents do not have money, they are encouraged to borrow; we will give them back the money when they come. But they still do not come" (Participant 1).

Parents' involvement and cooperation in caring for the children in institutional care is one of the biggest challenges faced by Cotlands. However, where parents are not willing to visit, Cotlands cannot force a parent to get involved. Where parents refuse to be involved, these children get better care in the institution than neglect they may experience if they remained with their parents. The above point clearly shows that it is not always the case that if a family is afforded the necessary assistance the family will assume its responsibility of caring for a child. Where a child might end up suffering from neglect from the family, institutional care might have to help care for the child.

The high cost of institutional care was one of the most negative aspects of the model. This was revealed in the previous chapter and in the preceding section on evaluation of CBC. Even though it might be expensive to care for a child in the institution, the quality of care the children in the institution receive is much higher than that received in CBC. Ironically, Cotlands' expansion of care to CBC has unintentionally resulted in the lowering of the quality of care provided to the children in the communities.

This point paves the way for exploring some of the positive aspects of institutional care that have hardly been explored by other researchers. Many researchers have criticised institutional care for its inability to provide psychosocial care to vulnerable children. Contrary to this, findings of this research revealed that Cotlands does provide psychosocial care to the children. Even though it might not be adequate and there are some challenges, to some extent children's psychosocial needs are met (as revealed in the previous chapter). In addition, findings of this study reveal that Cotlands is offering exceptional physical and medical care to the children in Cotlands institutional care. The children in the institution are offered quality care, this was

mainly in terms of the food they eat (one of Cotlands donors is Woolworths and education (Cotlands ECD was stocked with quality books, and other educational material mainly from donors). The ECD has adequate teaching staff and the classes were small enough to allow teachers to give attention to each child. The children's leisure activities included visits to zoos, swimming pools, and malls. Whilst the high quality of care in the institution is a strength for the organisation, a disadvantage is that, depending on how long the children would have stayed in the institution and become accustomed to a certain quality of care, they may find it difficult to adjust when they are reunited with their families who are mainly living in poverty.

The structure of institutional care makes it possible to monitor activities and the development of the children effectively. For example, the hospice, sanctuary, ECD and Cotlands management offices are in one building which is the head office. Cotlands house is less than 500 meters from Cotlands' head office. Centralization enables Cotlands to have greater control over activities in the organisation and the care provided to the children. It is easier, in terms of logistics, to attend to and monitor the children.

In addition, the researcher did not witness any form of child abuse in terms of the way the children are handled. This is contrary to what most researchers who argue against institutional care depict.

Having explored the successes and short comings of Cotlands' institutional care the next section explains findings from CBC. It reveals some of the things that are unsaid by most researchers advocating for movement towards CBC.

5.1.2 THE PRACTICALITY OF COMMUNITY-BASED CARE: WHAT IS UNSAID ABOUT THE MODEL

The literature has mainly focused on the negative aspects of institutionalised care, whilst the CBC has largely been praised. While this research could confirm some of the positive findings on CBC, it also found that there are challenges and barriers that complicate the provision of care. Before discussing the practical challenges, it is important to explore some positive aspects.

One of the strong arguments for CBC is that it is cost-effective and can accommodate a large number of children (Rayneke-Barnard, 2005). Cotlands calculations suggested that it costs over 20 times as much to care for a child in an institutional care as it does to meet his/her needs by providing home-based care services (Cotlands, 2009). In the institution, Cotlands has to incur the daily costs of raising children, the maintenance of the organisation and payment of employees such as care-givers. On the other hand, primary care-givers in CBC are provided with food parcels of plus/minus R100 a month, Cotlands does not have to pay primary care-givers nor incur many of the daily cost of raising children. Even though Cotlands pays care-workers and social workers [these employees are for the CBC only, to avoid work overload], the cost would still be much lower than institutional care.

Another cited advantage of CBC is manpower. Rayneke-Barnard (2005:66) argues that "more indigenous resources (in the form of manpower) must be tapped in order to address the problem of the children realistically and effectively." In practice Cotlands' manpower in CBC comes from grandparents, older siblings and the extended family, and in some cases the ratio of care-giver to child is relatively high. For example, in the families the researcher visited, the ratio varied between 1: 2 and 1:1, in some cases it was 1: 3. Therefore, the primary care-givers are able to interact and relate to every child on an individual basis. This is very important for the children's development of attachment.

Furthermore, the children are taken care of in their natural setting, that is, they are not taken away from their families and the environment they are familiar with. This is regarded as important for the children's development of social skills and installation of cultural values. In addition, caring for the children in their familiar environment protects the children from the trauma that comes with losing a family, and then living and being cared for by unfamiliar people.

Whilst the researcher acknowledges the above positive aspects of CBC that emerged from the study, it is important to reveal some practical challenges. These are mainly based on the researcher's observations.

As part of the participant observation, the researcher joined Cotlands' employees on one of their home visits. Below is the case study of Ntombi who was being visited because she had failed to take her child to two physiotherapy sessions (no real names are used).

33 year old Ntombi is an HIV positive mother living in a half- finished house in Soweto. She has two children of whom the youngest (2 year old) is HIV positive, epileptic and disabled. When we got into her house, both participant 11 and 12 praised Ntombi for the wonderful work she was doing. They commented on the fact that the baby was growing very well, was always kept clean and nicely dressed. Ntombi smiled. Participant 12 asked her to bring ARVs so that she could check for adherence. Ntombi commented on the extra medication that she had been given. Ntombi stated that she thought the medication was working well as she had no problems with the child. Both participants congratulated her for doing such a great job. Participant 12 then commented on the fact that the child had missed two physiotherapy sessions. Participant 11 sat in one corner with Ntombi and in a few minutes Ntombi started sobbing. She held Ntombi close and participant 11 mentioned to us that Ntombi felt that nothing was working out for her. Ntombi felt as if everything was going wrong. Participant 11 looked at the mother and consoled her 'you are doing really well my child, look at your child, look at her skin, so radiant and healthy. Everyone comments on how much you love your child. You are doing very well do not despair. 'Ntombi stopped crying and continued to talk to her. She told her that as the child continues to grow, she could not keep her at home forever, Ntombi would have to look for a job and the child would have to go to school. Ntombi mentioned that the nicest school that she thought would be convenient for her child was going for R800 a month. Participants mentioned that the school was too expensive. The mother said that she would take her child to that school or else she would teach the child at home herself. She stated that she could not send her child to any other school because she feared that her child would be abused or hit by the teachers or other children. Looking as if she was going to cry again, she stated that if someone abused her child she would never know because her child would never be able to tell her. She sobbed 'my child will suffer in silence. I would rather keep her at home'.

Participant 11 commented on the fact that the mother is over-protective of her child. She stated that the mother does not even allow her child to be put on the floor (which was made of cement). Ntombi did not want her child to get cold or to get germs from the floor. Participant 12 mentioned the fact that the mother should try not to be over-protective. She advised her that as the child grows, the child needs to be put on the floor where she can play and develop her other skills and senses. Participant 12 suggested that she would have to ask for a chair that can effectively support the body of the child. Both participants told the mother that a counselor was going to come to assist her. They stressed the importance of her taking the child for physiotherapy.

As we left Ntombi's house, looking sad, participant 12 said, 'I would not want that mother to despair, and I don't want her to give up. She is putting so much effort into her child. She loves her child and is doing well. One of the counselors has to talk to her'.

Whilst the two participants were leaving, participant 11 received a phone call from another Cotlands employee. The caller stated that one of their clients who was HIV positive and had a serious alcohol problem had left her 10 year old son with a note. The note stated that the child had to be sent to an organisation that could take care of him because she was not able to. The mother had abandoned her son who was also HIV positive.

The above case study highlights a number of sociological areas under investigation. Firstly, it highlights some of the emotional challenges faced by primary care-givers of children who are HIV positive and severely impaired. For most parents the anticipation of having a child is filled with intense joy, fantasy, great expectations and anxiety. However, this feeling is tarnished by not only the diagnosis of HIV but by the child's severe impairment. This alters the life and future of the family in ways that could never have been anticipated. The fact that Ntombi's child can never be like any other child is likely to fill a parent like Ntombi with endless sorrow which is indicated by her persistent feeling of sadness with varying intensity. The chronic sorrow could also be as a result of the fact that Ntombi feels guilty and blames herself for her

child's condition. As participant 12 told the researcher: "Ntombi feels that, had she not become HIV positive, her child would have been normal."

Beyond doubt, Ntombi's case shows the importance of the inclusion of primary care-givers in the provision of care. It proves what is argued by the ecological systems theory that a child cannot be assisted in isolation from his/her environment (the care-giver). One of the reasons for Ntombi not taking her child for physiotherapy could be as a result of her emotional instability. Hence, the only way Cotlands can ensure that its primary beneficiaries (children) are well looked after is by ensuring that those looking after the children are physically, emotionally and spiritually well empowered. It was therefore, important that Cotlands employees helped Ntombi to accept the child's diagnosis and try as much as possible to normalise it. Also Cotlands' interventions included those that could help Ntombi to move from guilt and self-blame. Constant praising of Ntombi was used to encourage Ntombi to develop confidence and coping strategies. In addition she had to be helped to deal with her over-protectiveness of her child. To achieve this, the intervention of a counselor was regarded as crucial.

Other than the case of Ntombi, a case of an alcoholic woman who abandoned and also misused her child's child grant illustrates the practical challenges of CBC. Participants 11 and 12 explained how hard they had tried to assist this woman. At one point they had rehabilitated, she seemed to improve for a very short time, but she started drinking more than before. She would use the money she received for child support for alcohol. Participant 12 added that the client was not the only one; there are a number of Cotlands' clients with alcohol problems. These are mainly referred to other organisations for rehabilitation if the problem is so severe that the counselors cannot help. If there is no one else responsible to look after the children of people with serious alcohol problems, the children are sent to Cotlands residential care until the care-giver has found help and can ensure that there is no longer the risk of endangering the child. This challenge is also stated in Cotlands annual report:

> "The high incidence of alcoholism, with the resultant child neglect and abuse endemic in some communities, poses a serious challenge. It is difficult to make a significant impact in the community because care-givers do not often take responsibility for implementing

proposed interventions. However, for the sake of the children, we will persevere, with the assistance of other stakeholders wherever possible" (Cotlands, 2009:21).

Problems of neglect and alcoholism illustrated above that may endanger a child in CBC reinforces the fact that institutional care is crucial so that children can be placed in safety when the family set up compromises their health and safety. This point shows that both CBC and institutional care are important for providing care for vulnerable children in the context of HIV/AIDS.

Much of the literature asserts that a family is a fundamental group of society and natural environment for a child's growth and development. There is an assumption that if afforded the necessary assistance, it can fully assume its responsibility within the community (Beard *et al*., 2002) The above cases of an alcoholic woman who abandoned her child and others who abuse their children in the communities, despite the assistance in the form of rehabilitation and counseling given to them, disproves the statement by Beard *et al*. (2002) In such cases, even if a primary care-giver is assisted it does not mean that she/he automatically and will always assume responsibility. What emerges from this is that where there is a potential of endangering the child, the child is better off in the institution if there is no foster care available. Institutional care can be used for continuity of care, where other forms of care have failed, or unavailable for preventing the child from falling out of the safety nets.

In addition, participant 12 revealed that fear of being stigmatised among primary care-givers also affects the children's ARVs compliance. This participant also noted that some women are not able to tell the child's father about the child's status. Hence, the mothers tend to hide the medication at home and sometimes fail to give the ARVs on a regular basis. This is because the mother fears that the father would ask why the child is taking medication. Participant 12 stated that some fathers tend to be violent or abandon the family once they find out the child's, and presumably his ownHIV status. According to Participant 11, in such cases the whole family is counseled and the men are referred to men's organisations such as Men as Partners for assistance, but it is not in all cases that Cotlands succeeds in obtaining compliance. These challenges and the above-mentioned alcoholic challenges, show that whilst it is important to

deal with people as individuals, one of the reasons why it may be difficult for Cotlands to assist the people could be because the organisation may be targeting the individuals and not effectively including the families, the friends and community. Communities, including family and friends play an important role in either worsening or helping an individual's situation, hence, they should not be excluded from the solutions/interventions

Contrary to the situation in institutional care, where compliance is strictly monitored and evaluated and where someone is held contractually accountable if there is failure to provide adequate care, in the communities it is very difficult to force people to comply and to hold someone accountable when there is no compliance. If there is no cooperation among the primary care-givers, the child's needs remain unmet and the child remains vulnerable.

In addition, Participant 9 stated that people's cultural beliefs and values are some of the stumbling blocks facing the counselors at CHBH. These beliefs and values make counseling very difficult. For example, some mothers or care-givers would state that some Zulu men do not believe in using condoms (Participant 9). In addition, the participant stated that despite counseling and prevention knowledge given to the mothers, most are not able to negotiate the use of protection such as condoms in their marriages. As a result a significant number of children are born HIV positive. The implication of this is that the number of vulnerable children keeps increasing rather than decreasing.

These findings reveal that it is very difficult to change the mind set of people, especially when it comes to cultural practice and values. This has been ignored by most researchers advocating for CBC. In addition, it is most difficult to tackle challenges that are embedded in cultural beliefs by targeting individuals. It might be more effective to start by changing the minds of the leaders moving downwards.

Participant 15 also stated that,

> "The biggest challenge is that when you start rendering a service and providing material such as food parcel, clothing etc this results in dependence of clients on the organisation.

This results in them not seeking employment and not wanting to become self-sufficient. Very few people have continued with the self-sustainable projects they started".

Backing up the above arguments, another participant stated that programmes are put in place for the clients to access but this they do not do (participant 11). This participant also pointed out that many of the primary care-givers accessed support groups when they were given incentives such as lunch and about R20, but once this was stopped, very few of them continued making use of the groups (Participant 11). Yet, this was established as a platform for the community people to get together, discuss their problems and find solutions. Their response is very negative as they do not realize the importance of a support group structure. In addition, the clients are so highly dependent on government grants and Cotlands services that they do not realize the importance of them striving to be self-reliant. The client's over-dependence on Cotlands threatens the organisation's sustainability and the effective provision of care to the children.

To emphasize the above point, participant 15 stated that that no matter how much assistance they are given, it is rather unfortunate that "community people most of the time do not see a way out of their current situation, they don't think it is possible and that hinders service delivery since they do not believe that any change is possible" (Participant 15).

The above accounts show Cotlands' and the participants' frustration in an attempt to assist the clients. The revelation of the fact that community people do not see a solution to their problems even if they are educated and given programmes that would enable them to do so, disproves what has been stated in the literature. Beard *et al.* (2002) and Desmond and Gow (2001) state that core to the CBC approach are self-help activities for income generation, being part of a support group and community development. The argument behind these programmes is that, when people are empowered and made self- reliant, in the long run, they would be able to identify and solve their own problems (Russel & Schneider, 2000). Contrary to this, most people in the communities, as revealed by Cotlands, are so entrenched in the problems that they do not see a way out.

It seems as if some clients do not have an interest in Cotlands projects, or they do not completely understand how the projects would benefit them, or that the clients have a tendency of accepting to embark on the projects without fully understanding what projects involve. There is a need for a test measure that Cotlands can use to assess if a person has acquired enough understanding of the projects before starting. Cotlands might also need to review its training programmes.

According to participant 9 some mothers or care-givers give the counsellors wrong addresses and telephone numbers. Therefore, the counselors are not able to get hold of patients for follow ups or if the patients fail to bring their children for checkups or if there is non-compliance with taking of ARVs. Some of the reasons for lack of cooperation by clients that were cited by most participants were fear of stigma and being labeled. In some cases, people do not want to be viewed as weak and helpless. Furthermore, one of the probable reasons for clients' reluctance or unwillingness to use Cotlands' counseling services could be because of cultural differences with regards to help-seeking behaviour. The literature reveals that about 80% of the South African, African population consult with traditional healers for psychological, spiritual and medical assistance (Gilbert *et al.*, 2010). Whilst this may be beyond Cotlands' control, the South African government may have to find ways of incorporating traditional healing into its health care system.

As long as these problems exist in the community the children will not benefit from the services provided and they might end up falling through the safety nets. The problems in CBC are many, and there are few social workers and community care workers to attend to all the problems. As proven from the above citations, the number of social problems within communities is overwhelming. The fact that it is difficult to change people's mindsets and to address people's individual problems is an important point that has not been taken into consideration by those scholars who view community-based care as homogenous and unproblematic.

Figure 3 summarises finding from Cotlands institutional care and CBC. It provides a comparison between the two models of care.

Figure 3. Comparison between Cotlands institutional care and community based care

Institutional care	**Community based care**
High cost to run	Low cost to run
Accommodates a limited number of children	Accommodates a larger number of children
Difficult to involve parents in care of a child	Easier to involve family in a child's care
Quality of care a child receives under the control of Cotlands	Quality of care a child receives highly dependents on cooperation of a primary care-giver
A child's relationship with people outside the institution is limited	A child generally has a web of relationships with neighbours, the church, the immediate and extended family , and other
In the institutional environment a child's exposure to cultural practices and traditions may be limited	In the community environment a child may be more easily exposed to cultural practices and traditions
Its centralized nature means that the provision of holistic care is facilitated and care-giving activities closely monitored.	Its decentralized nature makes holistic care provision and monitoring of care-giving activities more difficult
As a result of the formal nature of care provided, every caregiver and employee has a duty and responsibility to fulfil, hence it is easier to hold someone contractually accountable if care is not provided or if something goes wrong	As a result of its informal nature, it is very difficult to hold primary caregivers accountable if a child's needs are not met.
The routinised and regulated nature of care provision makes it difficult for children to adjust when placed in a more flexible environment with fewer rules and regulation	There are fewer rules and regulation because children grow in a natural environment
Child to caregiver ratio is comparatively high(specifically where all children are babies). Therefore, it limits the one on one interaction which is important for development of attachment.	Even though there may be exceptions, child to care-giver ratio is low Therefore, a child can easily develop attachment.
As a result of the fact that the organisation does not have to go through secondary parties (primary caregivers) to provide a child with care, a child can effectively benefits from services provided by Cotlands	As a result of the fact that the organisation has to go through the primary caregivers to provide care for a child, it sometimes becomes very difficult for a child to benefit from the services if the primary caregiver does not cooperate. Cotlands has to address the primary caregiver's problems so that the child can receive the appropriate care.

From the preceding table, each model of care has its own strengths and weakness. In the context of HIV/AIDS, both models of care are important. Where CBC is unable to provide care for a child, institutional care has to be used temporarily.

Mainly through the use of practical examples derived from the Cotlands case study, this chapter presented the challenges and strengths of both institutional and community-based care in meeting the needs of vulnerable children in the context of HIV/AIDS. The chapter demonstrated that institutional care is not totally detrimental to children and that community-based care is not as effective and unproblematic as generally argued by scholars. Thus both models of care are found to be very important in meeting the specific needs of children in the context of HIV/AIDS.

CHAPTER 6: SUSTAINABILITY AND EFFECTIVENESS OF CARE PROVIDED BY COTLANDS

This chapter presents findings on the sustainability of Cotlands and the care it provides. It also evaluates the effectiveness of care provided by the organisation.

6.1 SUSTAINABILITY OF COTLANDS AND CARE SERVICES IT PROVIDES

No matter how excellent Cotlands' projects or services may be, without sustainability, all efforts would be in vain. Hence, sustainability does not only refer to the sustainability of the organisation but rather to the benefits received by Cotlands' clients (Cotlands, 2009). Cotlands has put a number of measures in place to ensure that the organisation survives and that it continues to offer the children holistic care. These measures are explained below.

The first step in ensuring sustainability of the organisation and care provided by Cotlands was its movement towards CBC. There is no doubt that institutional care is very expensive and that it may threaten the survival of the organisation. Participant 18 reinforced this by commenting "If we are to continue serving as many children as possible, we need to double our efforts to deliver only the most cost-effective programmes." . In this regard in 2009, "Cotlands pledged to shift its focus and available funding to community care and to peg its residential services at their current capacity" (Cotlands, 2009). Cotlands' decisions are in line with recommendations and advice from international organisations, research findings, and from donors. Secondly, as stated by Participant 13, the South African government, in an effort to encourage a movement towards CBC, has offered to fund only CBC projects and institutional care projects that are already in existence. The government "wishes to rely on the extended family or other members in the communities to care for orphans" (Rayneke-Barnard 2005: 66). By so doing, new institutional care programmes would not obtain funding from the government. This implies that if Cotlands needs more funding from the government, most of its projects have to be community-based.

The aim of the organisation, through the use of CBC, is to educate its clients on how to care for their children and help them to become self-reliant and self-sustainable socially and economically. Once a family is empowered and is able to provide care for their child/children, the family is discharged. This creates opportunities for others to be helped and the organisation can be sustained. However, the unwillingness of some of the primary care-givers to engage in self- sustainable projects is a huge challenge for the sustainability of the organisation. To ensure sustainability of its services, Cotlands has had to deal with the fact that its secondary beneficiaries are becoming increasingly dependent on Cotlands for material aid (Cotlands, 2009). According to the 2009 Cotlands

> "This dependency is not only disempowering for the care-givers, but also threatens the long-term sustainability of the organisation, both financially and in terms of capacity. Families that rely on Cotlands for material aid cannot be discharged from the programme, which reduces opportunities for new referrals to be accommodated" (Cotlands, 2009: 8).

The organisation had to cut down on material aid given to the clients where possible. It also had to encourage capable clients to find employment and to be involved in income-generating projects.

Cotlands' third sustainable strategy is that instead of relying on one sector for funding, the organisation has had to develop a broad donor base. "Cotlands draws its income from a sound spread of resources – government funding, corporate funding, local and international trusts, bequests and individual giving" (Cotlands, 2006:12). According to participant 13, fifteen percent of Cotlands' budget is obtained from the government, seventy percent from donors and about fifteen percent is generated by offering training courses in Cotlands' areas of expertise.

Fourthly, cutting down costs can be an effective way for Cotlands to enhance sustainability. Without seriously compromising the care it provides, the organisation has had to cut down on spending. From 2008 Cotlands no longer collects donations of household goods, and clothing because of the cost of collected them was much higher than the value of the goods. Instead, donors are encouraged to drop off their donations at Cotlands. Children's school transport has

been outsourced. Such measures contributed to a 23% decrease in fuel costs, that is, from 31 987 litres to 24 496 litres in the 2008 financial year (Cotlands, 2008). During the recession of 2009, instead of Cotlands reducing the services they offer to clients, the organisation did not offer performance bonuses or salary increases to its employees. Whilst cutting down on costs is very important for Cotlands' sustainability, cutting performance bonuses and salaries of employees who are not paid competitive rates, could lead to low morale among employees. This could contribute to the high turnover the organisation is experiencing and may also impact negatively on the quality of care the employees would give to the children and other clients. While it is important for Cotlands not to compromise on the quality of care provided for the clients, equally important is the retention of its present care providers. Therefore, it may be important for Cotlands to make it up to its employees in one way or the other when its financial situation has improved.

In 2010, the organisation introduced the following measures to ensure that it continues to grow and that it is sustainable. As stated in Cotlands 2010 annual report, firstly the organisation introduced financial planning processes that included budgeting and forecasting. Secondly it had to budget for a surplus. The "surplus exists to ensure sustainability of the organisation's services, which is essential for good governance" (Cotlands, 2010). Over the years the organisation has recorded the following net surpluses: "R704 358 in 2003, R220 752 in 2004, R412 272 in 2005, R269 055 in 2006, R497 883 in 2007, R980 547 in 2008, and R6 607 881 in 2010" (Cotlands, 2010:56). The figures reveal that between 2003 and 2006, the organisation's surplus has been fluctuating, however, in 2007, 2008 and 2010 there has been an increase. The increase in surplus is not only because of higher income obtained as the organisation grows, but also as a result of mechanisms put in place to cut down on cost. To ensure sustainability, as the organisation continues to grow, the surplus is on the increase so that the organisation will have enough money to take it through the next few years in the case of market uncertainties.

Despite the measures put in place to ensure that Cotlands has enough finances for sustainability, the organisation has not been immune to the effects of a global recession. This is as a direct result of the fact that the bulk of Cotlands' budget comes from donors. As stated by Cotlands Chairman, Dumisani Ncala (Cotlands, 2010:4) the retrenchments faced by some of

Cotlands' donors "brought financially tough times to the organisation's ability to fundraise." As a result, in 2009 the organisation had a deficit of R1 213 878.Participant 13 stated that in 2010 Cotlands was running at about R5 000 000 behind budget. Regardless of this, the organisation did whatever possible to continue offering the proposed holistic care to its children.

6.2 ASSESSING THE EFFECTIVENESS OF COTLANDS' CARE

As stated earlier, the effectiveness of Cotlands' programmes and initiatives could only be assessed through the perspective of Cotlands' employees with an emphasis on evaluating the extent to which Cotlands addresses the challenges and characteristics of the disease in terms of caring for the vulnerable. A number of questions were provided as guidelines. As revealed from the literature review and for the purpose of this study, care is conceptualised in terms of the maintenance of social reproduction and, the development and utilisation of social capital. These concepts were used to assess the effectiveness of Cotlands' caring mechanisms.

6.2.1 MAINTENANCE OF SOCIAL REPRODUCTION

Literature reviews that, one of the impacts of HIV/AIDS is the destruction of social reproduction (Ansell, 2008). For this study, social reproduction is defined as "activities, attitudes, behaviours, emotions, responsibilities and relationships directly involved in the maintenance of vulnerable people's lives on a daily basis and intergenerationally" (Brenner & Leslett, 1989, cited in Makape, 2008:22). Social reproduction includes the passage of skills, knowledge and values from one generation to another. It also includes ensuring that food, clothing, and shelter are made available for immediate consumption.

The findings of this study reveal that through a range of processes focusing on children in both institutional and community based care, social reproduction is fostered by Cotlands. These processes include those that focus on the children's day-to-day physical sustenance such as the administration of medicine. Whilst the provision of physical maintenance through the provision of ARVs is working effectively in the institution, ARV compliance seems to be challenging in

CBC. With regard to ensuring the children's day-to-day sustenance, Cotlands provides children with nutritional food and nutritional supplements if needed, medication (ARVs), clothing and shelter.

The establishment of income-generating projects for its secondary beneficiaries is Cotlands attempts to provide measures against economic distress and to ensure that the society continues to reproduce itself. Cotlands' income-generating projects include: food gardens, jumble sales, mosaic work and so on. However, the sustainability of these projects is highly questionable because most of the people involved are not willing participants. A serious dependency problem amongst the secondary beneficiaries further hinders the sustainability of these projects. However, Cotlands helps it's beneficiaries to obtain grants such as foster care, child support, dependence and unemployment assistance and for this it has been highly successful.

According to Ansell (2008) one key way of achieving social reproduction is through education. The introduction of ECD, remedial programmes, monitoring children's performance at school and the implementation of necessary interventions reveals that Cotlands' re-conceptualisation of care includes the notion of reviving social reproductive capacity. If effectiveness is measured in terms of entering main stream school, the effectiveness of the programme is highly questionable because a substantial number of children have failed to enrol in mainstream school. This has two implications, firstly, it may mean that there is insufficient education provided by outside providers (teachers in the surrounding schools the children attend), or ongoing challenge or the effects of HIV & AIDS on children's brains and intellectual capability may be difficult to reverse. If HIV/AIDS has irreversible effects, Cotlands might have to find funding and focus on building a child's talent that does not necessarily have to be intellectually inclined.

Through empowering primary care-givers to care for their children, Cotlands also ensures that social reproduction is maintained. However, lack of cooperation among the primary care-givers(cited in the previous chapter) makes the provision of care ineffective. As long as the clients are not willing to cooperate, the child remains vulnerable.

Cotlands' passing of skills to primary care-givers is also a way of maintaining social reproduction. Primary care-givers are taught to administer medication, treat minor illnesses, cook nutritious meals for a child and also how to fend for their families (income-generating projects). Where families have been cooperative, this has been effective. However, lack of cooperation from many clients, cultural beliefs and practices, and fear of stigma and discrimination inhibit clients from accessing and utilizing services offer by Cotlands. In such cases, some children in CBC have not been able to benefit effectively from the services rendered by Cotlands.

6.2.2 PROVISION OF SOCIAL CAPITAL

This study intended to assess the extent to which Cotlands' care provide social capital. For this study, social capital is defined as "consisting of features such as interpersonal trust, norms of reciprocity, and social engagement that foster community and social participation and can be used to impact a number of beneficial outcomes" (Carpiano, 2006:165).

The establishment of social networks between Cotlands and other organisations is a key component of social capital. As stated in chapter 4, Cotlands' reconceptualised care relies heavily on collaboratively working with the South African government, the Chris Hani Baragwaneth hospital, other NGOS such as SOS Children's Villages, St Mary and with international organisations such as WHO. It has also collaborated with families and donors. This has enabled Cotlands to benefit financially and the organisation has been able to expand its provision of care. Interaction with other NGOs has enabled Cotlands to build mutual trust and share information so as to assist vulnerable children effectively. In addition, by working with the NGOs, Cotlands is able to refer /transfer older children to these NGOs for long-term care and is able to create opportunities for other vulnerable children to be assisted. Where social capital seems not to be working effectively is with regards to the social network among Cotlands, families and communities. Challenges depicted in previous chapters, reveal that there seems to be limited trust, confidence and cooperation on the families' side. Hence, provision of care to children in the communities has been a big challenge for Cotlands.

The establishment of support groups is an attempt by Cotlands to secure the inclusion of social capital. Intended benefits from the support groups include disclosure, adherence to ARVs, and a sharing of information and finding creative ways of solving their problems. However, social groups have not been very beneficial to the clients because of the clients' unwillingness to use the service.

In conclusion, findings of this study revealed that, to a large extent, provision of care in the institution has been more effective than in the communities. Nevertheless, Cotlands has to continue finding strategies to make CBCs effective.

CHAPTER 7: CONCLUSION AND RECOMMENDATIONS

7.1 CONCLUSION

The essence of this study was to explore how Cotlands has re-conceptualised care for vulnerable persons, especially children, in the context of HIV/AIDS. The findings have revealed that HIV/AIDS has had a huge impact on the organisation's activities. As the challenges of HIV/AIDS continued to evolve, so has the care provided by Cotlands. It is important that the organisation changed and continues to change because it would be likely to be ineffective in addressing the challenges South Africa is facing today in terms of caring for the children and their families if it had not done so.

As the effects of HIV/AIDS took its toll on the organisation in the mid-1990's, Cotlands moved from focusing on only one component of care which was physical to offering holistic care. To date, Cotlands' holistic care is supported by three pillars of service, that is, health, education and psychosocial needs. Effective provision of this holistic care would not be possible without the cooperation and commitment of a multidisciplinary team. Each of these employees brings unique skills and expertise to the team which is essential for meeting the needs of vulnerable children in the context of HIV/AIDS.

As the number of vulnerable children increases, CBC has become the most cost-effective model of care. Unlike, institutional care CBC allows a child to be provided with care in his/her natural environment by people he/she is familiar with. Effective functioning of CBC largely depends on the partnership and cooperation between Cotlands and the child's parents or primary care-giver in providing care. Cotlands' shift from caring only for primary to secondary beneficiaries has been a fundamental one to its re-conceptualisation of care.

However, this fundamental shift has brought challenges so immense that it has complicated the model of care debate. The case of Cotlands illustrates that even though CBC has proved to be the most cost-effective model, the barriers and challenges embedded within communities proves that this model cannot be used as a quick fix solution. Communities are not as

unproblematic entities as most advocators of CBC assume. Even though they may be homogenous, individual problems such as high incidence of alcoholism, child neglect and abuse, refusal to find employment, discontinuation with self-sustainable/empowerment projects and lack of cooperation with regard to accessing services provided by Cotlands such as social groups, pose serious challenges for Cotlands. In such cases, CBC may be the cheapest model of care, but it is less effective given that the challenges endemic in the families inhibit the interventions that attempt to meet the child's needs. In addition, the social problems within CBC are so overwhelming that they contribute to high turnover and burnout amongst the employees. Despite the challenges, CBC is still the new model of care for Cotlands that might be capable of success or of becoming effective as long as the organisation keeps evaluating the model and finding means of overcoming the challenges presented through its application.

The literature often states that institutional care should be done away with. For this reason the question of whether or not Cotlands can do away with institutional care completely was posed in this study. Findings confirm the need for a continuum of care for children who are faced with the following problem: children are abandoned as a result of their HIV status or the status of their parents; abuse and neglect, adult alcoholism that endangers the children; foster care is limited and it takes long for children to be fostered; and there is no one to adopt the children. Where children's lives may be endangered and there is not alternative care for the child, institutional care may be needed. However, where possible, the number of children in the institution has to be kept to a minimum. It has to be used as a last resort because it is very costly. It costs Cotlands 20 times as much to care for a child in an institutional programme as it does to meet the child's needs by providing home-based care. Institutional care should only be used as a temporary solution. This is because the model removes a child from his/her community of origin leading to alienation of the children from their cultural and social roots and roles which are essential for the child to develop into socially a productive adult. For this reason it is supported that Cotlands should no longer expand its institutional care, and instead improve and develop its CBC.

The case of Cotlands has revealed that, in the context of HIV/AIDS, caring for vulnerable children has become complex and multiple mechanisms/models of care have become crucial to

address the children's vulnerability effectively. There is a great need for individual people, other organisations and businesses to reinforce the work done by Cotlands. There is a need to help maintain and support organisations like Cotlands to continue to provide care for vulnerable people. It is the researcher's fervent hope that the contribution of this research does not only uplift the organisation's legacy of good work in the institution and in the communities, but Cotlands continues to grow from strength to strength.

7.2 RECOMMENDATIONS

In light of the findings of this research, it is recommended that:

- Even though it is essential in the context of the disease, CBC has numerous challenges that may make it less effective in providing care for vulnerable children. Such as the fact that primary care-givers are not making use of the services provided for them. It is therefore, highly recommended that Cotlands establish a test measure to assess if a person has acquired enough understanding of the programme, the reason for the intervention, and its intended end result before the service is provided. Cotlands needs to ensure that people buy into its programmes and are completely motivated to make use of its services. Cotlands also needs to evaluate its income generating and support groups programmes to determine where problems lie and how they can improve to the benefit of the CBCs.
- Currently, Cotlands' care-givers are not allowed to take children in residential care to their homes. Given the cited disadvantages of residential care and the fact that care-givers out-number the volunteers, the organisation should also allow the care-givers (on a voluntary basis) to take the children to their homes for a day or for the weekend. This may help Cotlands open its avenues of intervention as it will allow the children in residential care to be exposed to regular families.
- Cotlands' secondary beneficiaries mainly comprise primary care-givers who are predominantly female. However, the findings of this research reveal that, in a patriarchal society (such as South Africa), disclosure and ARV compliance are negatively impacted on by gender hierarchies and inequality. Therefore, it is highly recommended that more men get more involved in Cotlands' activities. Cotlands could

strengthen partnerships with organisations such as Men as Partners, which specifically target men. Since men are part of the problem, they need to be part of the solution. Cotlands also needs to find ways of including whole communities in its intervention programmes, rather than merely targeting individuals within the community.

- Whilst it is acknowledged that Cotlands has limited resources to pay its employees at market value so as to retain them, the organisation needs to put emphasis on creating meaning. By doing this, its employees may be able to overlook the low salaries and concentrate on the contribution they can make to the children they care for. Cotlands needs to let employees know how important their job is and that their performance is crucial to the benefit of an overall success of the organisation. There must be an emphasis on creating a sense of meaning and this could be included as part of Cotlands' values. Whilst it is difficult for the organisation to pay more, the organisation could provide a substantial number of benefits such as subsidised education for dependents of Cotlands employees, and travelling and housing allowances. If long-term benefits are not financially viable, the organisation could give incentives and benefits such as long service awards after 10 years of service.
- Cotlands is considered as one of South Africa's top institutions. It has also won awards for excellent services. From my own observations, the organisation is doing exceptionally good work despite the challenges. However, many black people the researcher spoke to about Cotlands had no knowledge of the organisation. There is a need for the organisation to broaden its scope to attract a wider range of volunteers, adopters and supporters from the wider South African population.

Whilst this study has provided much insight into Cotlands and provided an evaluation of the models of care based on the analysis of Cotlands; an in-depth comparative study should also be considered in order to investigate the strengths and weaknesses of other NGOs' conceptualisation and implementation of community-based care as this might help find further strategies as how to improve the model of care in the South African context.

REFERENCE LIST

AIDS Foundation South Africa. (2008). HIV/AIDS in South Africa. Retrieved on 23 March 2010, from http://www.aids.org.za/hiv.htm#4.

Anderson, B.A.& Phillips, H.E. (2006). *Trends in the percentage of children who are orphaned South Africa: 1995–2005.*Report No. 03-09-06. Pretoria: Statistics South Africa.

Ansell. N. (2008). Substituting for Families? Schools and Social Reproduction in AIDS-affected Lesotho. *Antipode*,40(5): 802–824.

Avert, 2011. HIV and AIDS in South Africa. Retrieved on 15 March 2011, from http://www.avert.org/aidssouthafrica.htm.

Averting HIV and AIDS (2010). The impact of HIV/AIDS in Africa. Retrieved on 17 October 2010, from www.avert.org/aids-impact-africa.

Babbie, E. & Mouton, J. (2001). 'The ethics and politics research': *In* Babbie, E. & Mounton. J. *The practice of social research*. Cape Town: Oxford University Press.

Barnett, T. &Whiteside, A. (2000). *Guidelines for studies on social and economic impact of HIV/AIDS*. Geneva: Joint United Nations Programme on HIV/AIDS.

Beard, B., Beard, J., Dimmock, F., & Streshley, L. (2001). *Models of Orphan Care in Malawi*. Retrieved on 17 October 2010, from: http://www.ccih.org/compendium/models.

Bendix, S. (2007). *Labour relations in South Africa* (4th). Cape Town: Juta.

Bigshoes.(2006). *Children's homes outreach medical programmes. A promising future improving the medical care of orphaned and vulnerable children (OVC) especially*

those affected by HIV/AIDS. Retrieved on 19 November 2010, from www.bigshoes .ac.za.

Binagwaho, A. &Ratnayake, N. (2009). The role of social capital in successful adherence to to antiretroviral therapy in Africa. *PLoS Med*, 6(1).

Boon, H., Ruiter, R. A.C., James, S., Van Den Borne, B., Williams, E.& Reddy, P. (2009). The impact of a community-based pilot health education intervention for older people as caregivers of orphaned and sick children as a result of HIV/AIDS. *The Journal of Cross-Cultural Gerontology, 24: 373-380.*

Bowlby, J. (1969). *Attachment and loss.* New York: Basic.

Bradshaw, D., Johnson, L., Schneider, H., Bourne, D., & Dorrington., R. (2002). *Orphans of the HIV/AIDS epidemic: The time to act is now.* Cape Town: Burden of Disease Research Unit, Medical Research Council.

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press.

Brown, K. (2009). *The Risk of Harm to Young Children in Institutional Care*. Save the children: UK.

Burawoy, M. (1998). The extended case method. *Sociology Theory*, 16(1): 4-33.

Carpiano, R.M. (2006). Towards a neighbouring resource-based theory of social capital for health: Can Bourdieu and sociology help? *Social Science and Medicine,* 62: 165-175.

Colton, M. & William, M. (1997). The nature of foster care; international trends. *Adopting and fostering*, 21(4): 44-49.

Cotlands annual report. (2001). Retrieved on 28 February 2010, from http://www.cotlands.org/index.html.

Cotlands annual report. (2006). Retrieved on 21 February 2010, from http://www.cotlands.org/index.html.

*Cotlands annual report.(*2007). Retrieved on 10 March 2010, from http://www.cotlands.org/index.html.

Cotlands annual report.(2008). Retrieved on 10 March 2010, from http://www.cotlands.org/index.html.

Cotlands annual report.(2009). Retrieved on 28 February 2010, from http://www.cotlands.org/index.html.

Cotlands annual report.(2010). Retrieved on 28 February 2010, from http://www.cotlands.org/index.html.

Cotlands: together we bring life. website (2011) Retrieved on 21 March from http://www.cotlands.org/index.html.

Creswell, J.W. (1994). *Research design: qualitative and quantitative approaches.* CA: SAGE publication.

Desmond, C. & Gow, J. (2001). *The Cost-effectiveness of six models of care for orphaned and vulnerable children in South Africa*. Durban: Health Economics and HIV/AIDS Research Division of the University of Natal.

Drimie. S. & Casale, M. (2009). Multiple stressors in Southern Africa: the link between HIV/AIDS food security, poverty and children's vulnerability now and in future. *AIDS CARE*, 21(s1): 28-33.

Engle, P. & Young., Tacon, S. &Yuster, A. (2004). *Bridging early child development and HIV/AIDS programming in Africa.* 15th International Conference on AIDS. Thailand.

Erasmas, V. (2009). *Development of a health snack for children with HIV/AIDS or compromised immunity*. Masters of technology dissertation. Vaal university of Technology. Vanderbijl Park, South Africa.

First sheet. (2004). Hospice palliative care in Canada. Canada: Canadian Hospice Palliative Care Association.

Foster, G. & Williamson, (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS*, 14(3): S275-S284.

Foster, S. (2002) Understanding community responses to the situation of children affected by HIV/AIDS—Lessons for external agencies, *In* One step further—Responses to HIV/AIDS.*SIDA Studies, 7*: 91–115.

Fox, S. (2001). *Investing in Our Future Psychosocial Support for Children Affected by HIV/AIDS. A Case Study in Zimbabwe and the United Republic of Tanzania.* Joint United Nations Programme on HIV/AIDS.

Freeman, M. & Nkomo, N. (2006). Assistance needed for the integration of orphaned and vulnerable children – views of South African family and community members. *Journal of Social Aspects of HIV/AIDS,* 3(3).

Gilbert, G., Selikow, T. & Walker, L. (2010). *Society, health and diseases in a time of HIV/AIDS.* South Africa: Macmillan.

Gillespie, S., Norma, A., Finley, *B. (2005).* Child Vulnerability and HIV/AIDS in sub-Saharan Africa: What We Know and What Can Be Done. *IFPRI*, 1-34.

Goldberg, S. (1993). Early attachment: a passing fancy or long-term affair? *Canadian*

Goldfard, W. (1954). Psychological privation in infancy and subsequent adjustment. *American Journal of Orthopsychiatry,* 15: 259-255.

Gordon, S., Benner, P.E. & Noddings, N. (1996). *Caregiving. Readings in knowledge, practice, ethics, and politics.* Philadelphia: University of Pennsylvania Press.

Government Gazette. Republic of South Africa. (2008). Children's Amendment Act, 2007. 513 (30884).

Greenstein, R., Roberts, B. & Sitas, A. (2003). Qualitative research methods: *In* Greenstein, R. (ed). *Research Methods manual*. Unpublished.

Haddad, L. & Gillespie, S. (2001). *Effective food and nutrition policy responses to HIV/AIDS: what we know and what we need to know.* USA: Institutional Food and Nutrition Research Institute.

Harris, P.L. (1989). Children and Emotion: *The development of psychological understanding.* Oxford. Oxford Press.

Harsch E. (2001).*South Africa tackles social inequities. Some gains, but still a long way to go in overcoming apartheid's legacy*. South Africa: Africa Recovery.

Hawe, P. & Shiell, A. (2000). Social capital and health promotion: a review. *Social Science & Medicine,* 51 (6), 871-885.

Hise, G. (2005). *What is implied, what is unspoken when we reconceptualise*? Reconceptualising the History of the Built Environment in North America Conference.

Hlabyago, K.E. & Ogunbanjo, G.A. (2009). The experiences of family caregivers concerning their care of HIV/AIDS orphans. *Family Practise* , 51 (6).

Hong ,Y., Li X., Fang, X., Zhao, G., Zhao, J., Zhao Q, Lin, X., Zhang, L., &Stanton, B. *Care arrangement of AIDS orphans and its relationship with children's psychosocial well-being: evidence from rural China*. China: Health Policy & Planning.

Jamil, I. & Murrisa, R. (2004).*Building social capital in Uganda: the role of NGOs in mitigating HIV/AIDS challenges*. Paper presented at the international conference organized by the International Society for Third Sector Research (ISTR) in Toronto.

Johnson, R., Browne., & Hamilton- Giachritsis, C. (2006). Young children in institutional care at risk of harm. *Trauma , Violence and Abuse*. 7(1): 34-60.

Joint United Nations Programme on HIV/AIDS. (2009). Report of 2008 to 2009. Retrieved on 20 March 2011, from http://www.unaids.org/globalreport/Global_report.htm.

Joint United Nations Programme on HIV/AIDS (2010). Overview of the global AIDS epidemic". *UN report on the global AIDS epidemic.* Retrieved on 12 November, 2010, from http://www.unaids.org/globalreport/Global_report.htm.

Jones, M. (2011). Shocking figures show crippled youth. *The cape times*, 5th April,2011.

Kvalsvig, J.D., Chhagan, M. & Taylor, M. (2007). *Getting Down to Basics: Principles and Strategies for inclusion of children on Ant-retroviral treatment in the education system, and support for other children affected by HIV and AIDS.* UNICEF South Africa.

Loening-Voysey, H., & Wilson, T. (2001). *Approaches to caring for children orphaned by AIDS and other vulnerable children.* Report Prepared for the United Nations Children's Fund (UNICEF) by the Institute for Urban Primary Health Care (IUPHC).

Loewenson, R. & Whiteside, A. (1997). *Social and economic issues of HIV/AIDS in Southern Africa.* Harare: Southern Africa AIDS Information Dissemination Service (SAfAIDS).

Madzingira, N., Mamimine, P., Mkaronda, J. & Marimo, N. (2008). *Caring From Within: Key findings and policy recommendations on home-based care in Zimbabwe.* Ireland: Health and Development Network& Southern Africa HIV and AIDS information Dissemination service.

Makape, S.M. (2008). *Exploring formal and informal arrangements for orphans: a Study in the Maseru District.* A thesis in Master of Arts in Sociology. University of Witwatersrand.

Mann, J.M. & Tarantola, D.J.M. (1996). *AIDS in the World II*. New York: Oxford Press.

Maritz G. (2002).*Impacts of HIV/AIDS for Business Organisations: a strategic management approach.* Retrieved on 24 March 2010, from http://ujdigispace.uj.ac.za:8080 /dspace/bitstream/10210/291/10/11Chptr2.pdf.

Mathambo, V. & Richter, L. (2007) "*We are volunteering": endogenous community-based responses to the needs of children made vulnerable by HIV and AIDS.* Ireland: Commissioned by Children in Distress Network (CINDI) and Irish AID

Mnubi-Mchombu, C., Mostert, J & Ocholla, D. (2009). Information Needs and Information-seeking Behaviour of Orphans and Vulnerable Children and their Caregivers in Okahandja, Namibia. *African Journal of Library, Archives and Information Science,* 19(1): 39 – 52.

Morrison, A. (2008). *An exploration of caregivers' perception regarding the emotional development of 6-10 year-old children living in a Johannesburg institution.* A thesis in Masters of education. University of Witwatersrand.

Murray, J.S. (2010). Collaborative Community-Based Care for South African Children Orphaned by HIV/AIDS.*Journal for Specialists in Pediatric Nursing*, 15 (1).

Nannan N., Norman R., Hendricks M., Dhansay, M.A., &Bradshaw D. (2007). South African comparative risk assessment collaborating group. *South African Medical Journal*, 97(8 Pt 2):733-9.

Ncama B. P. (2005). Models of Community/Home-based care for people living with HIV/AIDS in Southern Africa. *Journal of the Association of Nurses in AIDS*, 16(3):33-40.

Ogden, J., Esim, S. & Grown, C. (2004). *Expanding the care continuum for HIV/AIDS: Bringing carers into focus.* New York: International Center for Research on women (ICRW).

Paquette, P., & Ryan, J. (2001). *Bronfenbrenner's Ecological Systems* Theory. Retrieved on 19 December 2010, from http://pt3.nl.edu/paquetteryanwebquest.pdf

Phiri, S., Webb, D. (2002). Chapter 15: The impact of HIV/AIDS on orphans and programme and policy responses. *In AIDS, Policy and Child Well-being.* UNICEF-IRC www.unicef-icdc.org.

*Policy framework for orphans and other children made vulnerable by HIV/AIDS in South Afric*a. (2005). Building a caring South Africa together. South African government document.

Proudlock, P. & Hall, C. (2011). Children's right to social security and social assistance. *In Statistics on children in South Africa*. Retrieved on 9 May 2011, from http://childrencount.ci.org.za/rights_social_grants.php.

Rayneke-Barnard, E. (2005). *Determining the fundamental needs of children orphaned and otherwise made vulnerable by the HIV/AIDS pandemic, in households.* Masters of Arts (Theology) dissertation. University of Pretoria. Pretoria, South Africa.

Reed, D. (2001). *Going beyond 'islands of excellence'? NGO scaling up: possibility, Constrains and opportunities. Case of a child welfare NGO, in the light of HIV/Aids epidemic Southern Africa*. England: University of Bristol.

Richter, L. & Sherr, L.(2008). *Children thrive in families: family centered models and support for orphans and other vulnerable children affected by HIVAND AIDS.* Joint Learning Initiative on Children and HIV/AIDS.

Russell, M., & Schneider, H. (2000). *A Rapid Appraisal of Community-Based HIV/AIDS care and support programmes in South Africa.* Centre for Health Policy, University of the Witwatersrand, Johannesburg.

SASS (2011). *Statistical report on social grants.* Report no. 39. Retrieved on 30 April, 2011, from http://www.sassa.gov.za/Portals/1/Documents/7ba11076-0a07-4328-9868-bbee49a41a70.pdf.

Schenk, K.D. (2009). Community interventions providing care and support to orphans and vulnerable children: a review of evaluation evidence. *AIDS Care*, 21 (7): 918-42.

Smit, R. Living in an age of HIV and AIDS: implications for families in South Africa. *Nordic Journal of African Studies.* 16 (2).

Smith, M. K. (2006). Community work. *The encyclopaedia of informal education*. Retrieved on 10 february, 2011, from www.infed.org/community/b-comwrk.htm.

South Africa: UNICEF (2008). *Protection for Orphans and vulnerable children*. Retrieved from www.unicef.org/South Africa/protection-6633html.

Soweto. (2010). Retrieved on 1 May 2010, from http://www.joburg.org.za/content /view/921/159/.

Spitz, R. (1965). *The first year of life. A psychoanalytic study of normal and deviant development of object relations*. New York: Internal Universities Press.

Tellis, W. (1997). Application of a case study methodology. *The Qualitative Report*, (3), 3.

Togom, D.K. (2009). *Challenges facing AIDS orphans in Nairobi Kibera slums.* Bachelor's Thesis. Turku University of Applied Science. Nairobi. *Psychology, 34* (3), 307- 317.

Tolfree, D. (2003). *Community Based Care for Separated Children*. Stockholm, Save the Children Sweden.

UNAIDS (2008). *Report on the global AIDS epidemic Executive.* Joint United Nations Programme on HIV/AIDS.

UNAIDS (2009).*AIDS Epidemic Update.* Retrieved on 23 March 2010, fromhttp://www.unaids.org/en/KnowledgeCentre/HIVData/EpiUpdate/EpiUpdArchive/2009/default.asp.

UNAIDS (2010). *South Africa launches massive HIV prevention and treatment campaign*. Joint United Nations Programme on HIV/AIDS.

UNICEF (2006). *Africa's Orphaned Generations.* USA: New York.

UNICEF. (2008). *Trainer's manual: psychosocial care of babies and young children living with HIV/AIDS.* South Africa: Department of health in collaboration with UNICEF.

USAID Southern Africa. (2007). *Orphans and vulnerable children mapping and directory*. Boston: RAAO.

Vallender, I. &Fogelman, K. (1987). *Putting children first. A volume in honour of Mia Kellner Pringle.* East Sussex: The falmer Press.

Van Dyk, A. (2008). *HIV/AIDS Care and Counselling – A multidisciplinary approach.* Pearson Education South Africa.

Van Donk, M. 2002.HIV/AIDS and Urban Poverty in South Africa. South Africa: Isandla Institute.

Villarreal, M. (2006). HIV/AIDS: a threat to the viability of the society. *Kybernetes,*.35 (½): 195-208.

Waerness, R. (1996). Analysis of models of care. *In* Gordon, S., Benner, P.E. & Noddings, N. *Caregiving: Reading in knowledge, practice, ethics and politic*. NY, SAGE Publication.

Welman, C., Kruger F., Mitchell, B. (2005). *Research methodology.* Cape Town: Oxford University Press.

WHO (1990) *Global programme on AIDS and Traditional medicine programme*. WHO report.

WHO Technical Report Series, 898. (2000). *Home- Based Long-term care*. Geneva: World Health Organisation.

Wing, J.K. (1981). From institutional care to community care. *Psychiatric Quarterly*, 53(2).

Appendix 1: Essential elements for realising orphans & vulnerable children's rights

These needs are based on Manfred Max-Neef's theory on human scale development (1991) which is used as a framework for understanding children's fundamental needs.

SURVIVAL
Food • A nutritious and balanced diet with 3 meals a day as an absolute minimum. • Involve children in the preparation and choice of food. *Involving children in the preparation of food is a synergistic way of meeting a number of needs &of honouring some of their rights – the right to survival, the right to participate in making choices and the right to develop a distinct individual identity as well as the right to be taught important life skills.*
Clothing
• At least one change of clothing that offers protection against the weather • Nappies *Nappies were not always considered a necessity – in rural settings toddlers were seldom seen with nappies. In residential settings, some preferred cloth nappies because they were less likely to cause skin irritations, whilst others preferred disposable nappies and received large consignments of them from foreign donors.*
Home environment
• Shelter against the weather. • Protection against environmental hazards, pests and intruders. • A personal and safe sleeping space which allows for privacy for older children. • Basic household amenities – access to running water and sanitation and access to fuel for boiling water and for warmth. • Cleanliness. • Spare bedding.

Spare bedding was especially needed for HIV+ children and for bed-wetters, which was common in residential settings.
Hygiene/infection control
• Positive personal hygiene practices. • Use of universal precautionary guidelines where there is risk of infection. • Access to water and sanitation. *Without close adult supervision, water and sanitation, children are unlikely to learn healthy habits. In some settings the adults themselves were unaware of hygienic practices – for example a child with diarrhoea was seen to defecate at the threshold of the household. The dog ate the faeces. In another instance the caregiver gave a child un-boiled water, collected from the river, to drink out of a communal cup.*
Treatment and health care
• Full immunisation and record of Road to Health Card. • Access to basic treatment and health care. • Reliable caregiver to administer medicines, dietary supplements and home remedies. • Awareness of, and response to indications of illness as well as basic first aid. *Access to health care was particularly difficult for sites in rural areas.*
SECURITY **Protection**
• Protection from abuse, neglect and exploitation. • Acceptance of the HIV positive child. • Protection against discrimination, and stigmatisation. • Arrangements to be made for the care of the child before the parent dies, including drawing up of a will / expressed wish nominating a legal guardian for the child and stipulating the child's inheritance. • A caring, constant and reliable adult presence with whom the child can disclose abuse, and who can access help for the child. • Healthy discipline practices including setting rules and limits. *While not mentioned as a right or need by participants in the study, theory and experience*

confirms that children should have healthy discipline practices to help them behave in culturally and socially appropriate ways.

Affection

A caring, constant and reliable adult presence, offering security and continuity and with whom the child can communicate openly.

- The adult caregiver to have a positive communication style which includes "being there" for the child, taking time to listen, and communicating at the child's level.

The caring and constant adult upholds many of the other rights of the child, including protection and identity. In addition, open communication at the child's level provides the basis for meeting other needs relating to understanding and participation.

SOCIALISATION

Identity

• Birth registration.

• Retention and respect for the child's name, kinship and identity.

• Captured memories for the child such as photos, artefacts, details of significant others and cultural connections.

• Acknowledgement of the individuality of the child, for example celebration of birthdays.

Legal identity, personal identity and cultural/social identity are all important.

Education/Schooling

• Free and accessible primary and secondary education.

• Advocacy for and protection of children's rights to free schooling.

• Time to go to school and time and space to do homework.

• An adult caregiver or older child to be available to do homework with the child.

• Entrepreneurship skills to increase capacity for self-sufficiency.

For many sites, school fees and school uniforms were viewed as essential elements, without which a child could not go to school. However, in terms of the Constitution, schools may not discriminate against or exclude any learner and therefore a school uniform should not be an essential element. Rather, what is essential is for the child to have someone who can advocate on his or her behalf and ensure their right to free education is realised. Children at sites visited requested help with homework.

Participation • Children to contribute to their own care plans – their views are to be sought and listened to. • Children are given opportunities to participate in all decisions affecting their lives. • Children to participate in social, cultural and kinship activities and occasions *Involving the child in decision-making around their care plan provides a sense of security and protection as well as a sense of future direction.*
Understanding, Information and Communication • Training for children in basic survival skills and life skills. • Caregivers to communicate, at least on a basic level, with children in the language of their community of origin. • Information and open communication with children about their own health status if HIV Positive. • Information and open communication with children on health issues, including sexuality and Relationships. *Being able to communicate with a child in the language of their community of origin has important implications for providing a sense of belonging, cultural connection and identity for the child.*
Counselling/supportive services • Support and guidance for children who are experiencing social and emotional difficulties and where caregivers are unable to provide this, to access appropriate assistance. • Communicate openly with children about death, of a parent, family member, friend or their own death and provide emotional and spiritual support. • Caregivers need to understand implications of loss and children's expression of grief. *Children are particularly vulnerable after the death of a parent – the right and need for protection, affection, support and understanding could be met synergistically by a caring responsible adult.*
SELF-ACTUALISATION

Recreation/Idleness

• Balance between household chores, recreation and leisure time.

• Time to play and to be children.

• Recreational opportunities with peers.

One of the worst scenarios depicted in this study was a girl child having to take responsibility for nursing her AIDS-ill mother, a baby with disability and a toddler. When asked how she could be helped– her reply was –"I just want to be able to play".

Children and teenagers learn, socialize and form a sense of self through play/recreational activities with peers.

Freedom of Expression

• Time and opportunities for children to question and discuss values, ethics and morals.

• Time and opportunities for children to be able to freely seek information and to express their ideas.

Some site representatives felt that children should be allowed freedom of expression, but within cultural and age-appropriate boundaries. However, the Convention on the Rights of the Child gives the child the right to freedom of expression without boundaries.

PALLIATIVE CARE

• A caring presence and pain relief during the transitional phase.

• Acknowledgement of death to children.

• Provision of opportunities for closure when a child, parent, family member or friend dies.

• After-death services including transport of body to mortuary and a dignified burial.

All sites visited in this study expressed difficulty in discussing death with children – whether it related to the death of the child him/herself or the parent or another child. It was often said that the adults themselves struggled with this and therefore found it difficult to help children to cope with death.

From Loening-Voysey& Wilson (2001:18-22).

Appendix 2: Permission letter

To the Director of Cotlands

RE: Request for permission to conduct research at Cotlands.

My Name is Dorothy Guvava. I am a Masters student in Health Sociology at the University of Witwatersrand. I request permission to conduct research at Cotlands for my research project titled: ***Re-conceptualising care for vulnerable children in the context of HIV/AIDS***.

Since its establishment, Cotlands has instituted outstanding developments and has achieved significant advances towards caring for people affected and infected by HIV/AIDS nationwide. In consequence, I find Cotlands to be an ideal organisation for my research project which aims to investigate how 'care' for vulnerable people has been redefined, modified and implemented in the context of HIV/AIDS. To this end, I would like to investigate how HIV/AIDS has presented challenges to Cotlands and how the organisation has responded to these challenges. This will involve exploring activities, programmes and initiatives that Cotlands has introduced to care for vulnerable people.

Firstly, I request permission to ***interview*** Cotlands' management and project leaders, care-givers at Cotlands Sanctuary, and care-givers at home-based-care programmes and hospice in Soweto. Written permission will be sought from project leaders of each initiative and each interviewee prior to conducting the interviews and observations.

Secondly, I request permission to ***observe*** activities at the training and education programmes in Soweto, and at the Sanctuary where I would like to be of ***assistance*** in care activities wherever you may require my assistance. This may include playing with the children, teaching, feeding, bathing and dressing them. I will endeavour not to disrupt normal functions of the organisation. Written permission will also be sought from the trainers of each programme and the beneficiaries of the training programmes.

Lastly, I seek your permission to conduct a ***document analysis*** of Cotlands' annual records, policies, strategic plans, brochures and other documents that will enable me to unravel how your organisation is caring for vulnerable persons in the Context of HIV/AIDS.

In order to guarantee confidentiality, the name Cotlands and individual participants will not be used in reporting findings unless permission is given by the organisation and the participants for the use of real names. Cotlands will receive a copy of the report.

It is my understanding that the study will not pose any risks. I will do whatever possible to ensure that Cotlands benefits from my services as a volunteer in activities that the organisation would like assistance in.

If you have concerns regarding the study or if you require any additional information, please contact:

Researcher: Dorothy Guvava

Tel: 076 752 8499 Email: pai_vim@yahoo.com

Study supervisors: Louise Hagemeier
Tel: 011 717 4431 Email: louise.hagemeier@wits.ac.za

Study supervisor: Kezia Lewins
Tel: 011 717 4457 Email: kezia.lewins@wits.ac.za

Your assistance in this regard will be highly appreciated.

Yours Faithfully

Dorothy Guvava

Appendix 3: Participant information sheet

Dear Sir/Madam

My name is Dorothy Guvava. I am a Masters student at the University of the Witwatersrand. I am conducting a research project entitled: ***Re-conceptualising care for vulnerable children in the Context of HIV and AIDS***, as part of the formal requirements for my degree. This study had been approved by the Director, Cotlands Head Office.

The aim of the study is to investigate how 'care' for vulnerable persons in the context of HIV/AIDS has been re-conceptualised by *Cotlands*. To this end, this study intends to explore how Cotlands has redefined, re-evaluated and modified the concept of 'care'. A review of Cotlands' responses to the epidemic through their various organisations and programmes will be undertaken, and the ways in which care is provided for infected and affected persons examined.

As you are involved in care activities at Cotlands, I believe your participation in this research will provide insights into Cotlands' work and into the challenges the organisation is facing with regards to caring for vulnerable people in the context of HIV/AIDS

I hereby request your assistance and participation in this research project. Your participation in this research would mean that you will be required to take part in an interview which will take approximately 1hour. Your participation in this research is voluntary. There are neither rewards for participation nor penalties for those who do not participate. The interview will be scheduled at the time and place that will be convenient to you. Should you not feel free to answer any question(s) or wish to withdraw at any stage during the interview, you are free to do so without facing any consequences.

Your names, identity and personal data will not be used in any part of the research. Names and positions of top officials will only be identified in the report by consent. All data collected through the interview will be treated in the strictest confidence. A copy of my research report will be available at Cotlands Head Office, a copy will be given to my supervisors and examiners; and another copy will available through the University of the Witwatersrand library.

This is not a job-related exercise nor is it a performance evaluation. If you have concerns regarding the study or if you require any additional information, please contact:

Researcher: Dorothy Guvava
Tel: 076 752 8499 Email: pai_vim@yahoo.com

Study supervisor: Louise Hagemeier
Tel: 011 717 4431 Email: louise.hagemeier@wits.ac.za

Study supervisor: Kezia Lewins
Tel: 011 717 4457 Email: kezia.lewins@wits.ac.za

Yours truly,

Dorothy D. Guvava

Appendix 4 - Participant consent form

Please indicate with a tick √ if you agree, or an X if you do not agree.

I hereby confirm that:

☐ I have been briefed on the research that Dorothy Dorothy Guvava is conducting entitled**: Re-conceptualising *care* for vulnerable children in the context of HIV and AIDS: A case study of Cotlands.**

☐ I understand what participation in this research project means.

☐ I understand that my participation is voluntary.

☐ I understand that I have the right not to answer any questions that I do not feel comfortable with.

☐ I understand that I have the right not to participate and the right to stop the interview at any time.

☐ I understand that any information I share will be held in the strictest confidence by the researcher.

☐ I understand that no information that would identify me will be released or printed without my permission.

☐ I hereby request that I be guaranteed anonymity.

Signed by……on ……..at …….
…… (Participant signature)
Signed by…….on……...at …….....
…….. (Researcher signature)

Appendix 5 - Interview schedule

A. An overview of how Cotlands has changed

1. Can you please tell me about Cotlands?
2. Over the years, how have Cotlands' mission and objectives changed?
3. To what extent has HIV/AIDS contributed to the changes?
4. What principles and values underpin Cotlands' care and support?
5. What criteria does Cotlands use to identify people to assist and what kind of help does it offer?
6. What models of care are used at Cotlands? Have these models always been used or have new regimes of care been introduced and why?
7. What do you consider to be major challenges facing Cotlands?
8. What challenges does HIV/AIDS pose to Cotlands?
9. How successful do you think Cotlands is, in addressing these challenges?

B. Changes to the forms of care

1. Who does Cotlands care for in institutions and who does it care for in communities?
2. How do care-needs or services provided to these people differ?
3. What are the advantages and disadvantages of caring for people in institutions?
4. Despite the negative publicity being given to institutionalised care, why is Cotlands finding it necessary to remain with this form of child care in terms of the Sanctuary and Hospice?
5. What are the advantages and disadvantages of caring for people in their communities?
6. To what extent have HIV/AIDS challenges, in terms of cost, influenced changes in Cotlands' models of care?
7. Does Cotlands have programmes or initiatives that target those living with HIV/AIDS? What do these programmes focus on?
8. Among people living with HIV, how do you help these people control the HIV to prevent it from developing into full blown AIDS?
9. Does Cotlands have programmes or initiatives that target vulnerable people who are HIV negative? What do these programmes focus on?
10. Does Cotlands have programmes that focus explicitly on HIV/AIDS prevention and those that focus explicitly on the treatment of HIV/AIDS? Please explain.
11. What programmes do you have that focus on silence, denial, stigma and discrimination?
12. What social facilities are available for people living with HIV/AIDS and those who are HIV negative? What are some of the benefits of utilising the social facilities for the users?
13. In your experience, what challenges do people living with HIV/AIDS face?
14. Which programmes attempt to address these challenges?
15. What challenges do vulnerable people who are HIV negative face?
16. Which programmes attempt to address these challenges?
17. Has there been any increase in the number of people utilising your services? Please explain.

18. What other changes have you noticed in the provision of care, in the context of HIV/AIDS?
19. How does Cotlands empower its beneficiaries?

C. Changes to employee recruitment and requirements

1. How many employees do you have?
2. Are these mainly part-time or full-time?
3. What proportion of these employees are full-time care-givers and how many are volunteers?
4. How many are males and how many are females?
5. From the time Cotlands started, have there been any major changes in the staff recruitment?
6. Did you at any stage face challenge(s) whereby Cotlands' staff numbers could not meet the demands of care giving? Please explain what the demands were?
7. How did Cotlands address these challenges?
8. How have the job requirements, attitude, behaviour, and skills of Cotlands' staff members changed overtime? What contributed to the changes?
9. What skills, knowledge and attitude does Cotlands most require to enable care-givers to offer care services to vulnerable people in the context of HIV/AIDS?
10. Traditionally, care-giving is known to be primarily a role of women in Africa. What role do you think men can play in care-giving in the Context of HIV/AIDS?
11. Do men and women play similar roles in Cotlands, particularly in care-giving? Please explain.
12. In your own opinion, do you think men should be more involved in care-giving? Why or why not?

D. Financial changes

1. What proportion of your funding comes from state-funding, fundraising, donations and other sources?
2. What proportion of Cotlands' budget is spent on Home-Based care in Soweto, the Sanctuary in Turffotein, Chris Hani Barangwath counselling project, Hospice and the training project in Soweto?
3. How does Cotlands make decisions about the proportion allocated to each of the above-mentioned programmes?
4. What are the organisation's major categories of expenditure?
5. Have there been any changes in these categories, and the amount spent on them? Why have there been changes, if any?
6. What proportion of Cotlands' expenditure is directly linked to care and care provision
7. What care activities have become most expensive?
8. Which care activities do you think Cotlands would want to spend more money on? Please explain.
9. Have there been any difficulties in obtaining funding? Please explain.
10. Have there been new opportunities that have opened up for accessing funding? Why / why not?

11. Have the challenges of HIV/AIDS had any impact on your fundraising?

E. Changes to care provided

1. What kinds of people do you care for?
2. What does care entail? How do you provide care for those you assist?
3. Are there any special skills or requirements you consider important for doing your job? Please explain.
4. If you care for both, people living with HIV/AIDS and those who are negative but vulnerable, do these groups of people have different needs? Please explain.
5. Are there any programmes that Cotlands offer that you find useful in enabling you to do your job?
6. What are some of the challenges you face in providing care for vulnerable people?
7. What is the hardest part of care-giving?
8. What is the most rewarding element of care-giving?
9. What would you like to do more of for those you care for?

F. Cotlands counselling

1. What role does counselling play in Cotlands?
2. How central do you think counselling is to the provision of care at Cotlands?
3. What needs do people with HIV/AIDS have for counselling?
4. What needs do vulnerable people who are HIV negative have for counselling?
5. Do any clients, patients or members of the community have a greater need for counselling than others? Please explain.
6. What challenges do you face?
7. What can be done to overcome some of these challenges?
8. Do you think you are sufficiently resourced to provide for people's needs?
9. What more can be done to assist vulnerable people in the context of HIV/AIDS?

G. CotlandsTraining programmes

1. What does your training programme focus on?
2. What activities form part of care-givers' training programmes and how do these activities aid the provision of care?
3. Are there different types of training programmes that you offer?
4. If so, what are they? Please describe each training programme?
5. Are there different programmes for those who care for HIV positive people and for those who care for vulnerable people who are HIV negative?
6. If there are, how do these programmes differ? Could you please describe in a little more detail what the training involves?
7. What skills and knowledge do you expect care-givers to gain from the training session?
8. To what extent do you think the beneficiaries of the training programmes are using the knowledge and skills offered at the training sessions to benefit the organisation?
9. What challenges are you facing?
10. How do you assess the success or otherwise of the training programme?

11. From your own experience where do you think your training programme needs to be improved? Please explain.

Appendix 6- Cotlands Time-line

1892

- Matron Dorothy Reece is born on 25 December in Firthcliffe, Orange County, New Jersey, USA as Dorothy Pearl Greenberg (later Reinberg).

1934

- Dorothy Reinberg marries Thomas Reece on 8 September at Johannesburg.

1936

- Matron Reece starts Cotlands after having treated children in her own home.

1942

- The Public Health Department requests Matron Reece to make alterations to the home. Unable to do this due to financial constraints, Matron Reece decides to close the home. After an appeal by the *Sunday Times*raised 4000 pounds (currency used at the time), the home was registered as a charitable institution.

1944

- Thomas Reece passes away on 23 July.

1952

- The home moves to a larger home in Kenilworth. Strict vetting procedures are put in place for prospective adoptive parents, due to a nationwide shortage of babies.

1953

- The sanctuary is opened.

1955

- *The Sunday Express* newspaper runs an article on 17 April headlined “Which would you save?” highlighting the plight of Cotlands. The article, featuring John Walker of radio fame, was run against the background of a protest march in Johannesburg due to the proposed closure of the Standard Theatre.

1958

- Babies from Cotlands attract a lot of attention at the Rand Easter Show when they are brought to the Cotlands wishing well.

1959

- Matron Reece is awarded the woman of the year award. Plans are also made for a new home.

1960

- Matron Reece retires.

1961

- Matron Reece gets the process going for the new Cotlands Baby Sanctuary building in Turffontein, Johannesburg on 22 March.

1962

- Cotlands institute baby care classes for prospective parents start.

1963

- In collaboration with the University of the Witwatersrand, Cotlands offers training in baby-sitting.
- The new Cotlands Building in Stanton Street, Turffontein is opened by MR. B.J. Vorster, the Minister of Justice.

1967

- Matron Dorothy Pearl Reece passes away.

1976

- An appeal is launched in the *Southern Courier* newspaper for more female volunteers at Cotlands.

1978

- Another appeal is launched in the *Southern Courier* newspaper, this time for support of Cotlands' fundraising efforts

1982

- Peter the Parrot, a pet of Matron Reece's and a Cotlands institution, passes away. An appeal is made to the public for the donation of another parrot to Cotlands.

1990

- Alta Le Roux takes the helm.

1993

- The Cotlands Nursery School opened.
- Beginning of the Impact of HIV/AIDS research project.
- Tin Project started.

1994

- Cotlands presentation to Nelson Mandela at Union Buildings.
- Launch of new corporate logo.

1995

- A telethon held by Radio 702 raises R1, 2 million for Cotlands.

1996

- The AIDS Hospice at Cotlands is opened.
- A billboard campaign is run with Highveld Stereo.
- Cotlands turns 60.
- Union representation for staff.

1997

- Formulated policy guidelines for children infected/affected with HIV/AIDS.
- Unveiling of Cotlands Memorial Wall at West Park Cemetery.

1998

- Started community outreach.
- Sold promo items for sustainable project.
- Joined Children's Charity Trust.
- Opened Human Resources Department.

1999

- Home - Based Care and Support in Gauteng and Hlabisa, KwaZulu-Natal.

2000

- Tin Project expanded to KwaZulu-Natal.

2001

- Cotlands turns 65.
- Quest for national presence and centre of excellence.
- First group of children start Big School.

2002

- Investigated need to open hospice in the Western Cape.
- Develop Training Department.
- Jackie Schoeman appointed as Executive Director.

2003

Implementation of Antiretroviral Treatment for relevant children.

- Opening of Western Cape Hospice in Somerset West.
- Launch of the Cotlands/Chris Hani Barangwanath HIV/AIDS counselling project.

2004

- Opening of Cotlands Nutrition Project in Eastern Cape.

2005

- Acquisition of Macassar Haven in Macassar, Western Cape.

2006

- Cotlands celebrates 70 years.
- Opening of Everest Early Childhood Development (ECD) centre in Mpumalanga.
- Opening of Cotlands House.

2007

- Opening of Cotlands Community centre in Soweto, Johannesburg.

2009

- Opening of Tirelong Early Childhood Development (ECD) centre in North West
- Opening of Toy Library in KwaZulu-Natal.

- Acquisition of property in Reeston, Eastern Cape.
- Partnership with St Mary's for older school-going children – the first group of children were transferred to St Mary's.

2010

- Cotlands celebrates the 2010 World Cup in South Africa with the world
- Macassar Haven becomes a community centre
- Opening of Toy Library in Eastern Cape.
- Opening of Toy Library in Gauteng.
- Acquisition of new property in KwaZulu-Natal.

2011

- Cotlands celebrates 75 years of service to orphaned and vulnerable children.
- Opening of Early Childhood Development centre at Macassar Haven community centre.

Source:http://www.cotlands.co.za/about/history/