

COMMUNITY-BASED CARE FOR HIV/AIDS ORPHANS

By

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DECLARATION

I, **Tshifhiwa Mamaila**, hereby declare that this dissertation for MSD (Social Development and Social Policy) at the University of Pretoria hereby submitted by me has never been previously submitted at this or any other institution. I swear that this is my own work in both design and execution. All reference materials contained therein have been duly acknowledged.

Signature: 

Date: May 2005

DEDICATION

I dedicate this research study to my Father and to the loving memory
of Atta and my Dear Mother Tshinanne.

I still wish you were here with me, you know.

I miss you dearly.

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God is good, God is great, His love is everlasting. Thank you Lord for the strengths, blessings and looking out for me.

I would sincerely love to say: “A ni ntshileli” to the following people:

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Thank you to Heartbeat and all the hard working staff members, caregivers, volunteer and the children, who willingly assisted me in this study. Thank you for your co-operation. Thank you Roz for your mastery in the Queens’ language and your time in editing my work.

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Joan, if it was not for you and what we went through together, I probably would not have gone this far. Thank you for the inspiration and the faith you had in me.

“Lo tsha. A sa shumi a songo la, hone-ha iwe u do la tsha biko lau. Ndaa”

ABSTRACT

Community-based care for HIV/AIDS orphans

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South Africa has been affected both economically and socially by HIV/AIDS. The South African government has put policies in place to support people infected and affected by HIV/AIDS and to ensure that they are not discriminated against.

Many children have lost either one or both parents to this pandemic. The purpose of this research study was to explore community-based care for HIV/AIDS orphans. The research question for the study was: “*What are the key components of community-based care for HIV/AIDS orphans?*”

The objectives for this study were as follows:

- To conceptualise community-based care for HIV/AIDS orphans.
- To determine the directions and limitations with regard to community-based care within the current policy framework for caring for children infected and affected by HIV/AIDS.
- To identify the components of Heartbeat’s model for community participation for community-based care of HIV/AIDS orphans.
- To determine the key components for effective community-based care in the care of HIV/AIDS orphans, to serve as guidelines for a sustainable community-based care model for these children.

This was an exploratory study. The researcher made use of a case study, which is a type of a qualitative research strategy. Twenty HIV/AIDS orphans, six caregivers and one volunteer were interviewed and a semi-structured interview schedule was used to gather data.

Some of the key findings for this study were the significance of community participation, care and support in the placement of HIV/AIDS orphans which guided the key components for sustainable community-based care for HIV/AIDS orphans. The study identified specific challenges in getting communities to participate in the care and support of HIV/AIDS orphans.

The study made the following recommendations based on the research findings:

- The revision of policies and guidelines addressing children infected and affected by HIV/AIDS.
- The drafting and implementation of monitoring and evaluation mechanisms for community-based care for HIV/AIDS orphans.
- The Government's involvement in pledging more resources for HIV/AIDS orphans.

Key words

Care and support

Caregivers

Children infected and affected by HIV/AIDS

Community-based care

Community participation

HIV/AIDS

HIV/AIDS orphans

Heartbeat's community-based care model

Guidelines for community-based care

Partnerships for community-based care

Rights and needs of HIV/AIDS orphans

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Chapter 1

INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 INTRODUCTION

South Africa has a serious Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic, with millions of its people living with the disease. The minister of health, Dr Manto Tshabala-Msimang, commented that the HIV/AIDS epidemic is the most important challenge facing South Africa since the birth of democracy (HIV/AIDS and STI's five years strategic plan document for South Africa, 2000-2005). Recent estimates suggest that of all people living with HIV in the world, 6 out of every 10 men, 8 out of every 10 women, and 9 out of every 10 children are in Sub-Saharan Africa (HIV/AIDS and STI's five years strategic plan document for South Africa, 2000-2005).

The University of Cape Town actuarial science models indicate that 5.35 to 5.4 million people are currently living with HIV/AIDS, rising to as many as 6.5 - 7 million over the next ten years (www.hivaids.co.za, 2004). According to the United Nations, South Africa has more people living with HIV/AIDS than any other country in the world (www.hivaids.co.za, 2004).

The American International AIDS Foundation (2004) provided the following statistics:

- 3.1 million men, women and children died from AIDS in 2002.
- 5 million men, women and children were newly infected with HIV in 2002.
- 25 million children will be orphans by 2010 because of AIDS.
- 42 million men, women and children currently living with HIV/AIDS.
- 70 million men, women and children may die of AIDS in the next 20 years.

Over the past decade, HIV prevalence estimates in South Africa have been largely derived from an annual survey of pregnant women attending antenatal clinics, supplemented by additional estimates from workplace and other studies, according to The Human Sciences Research Council (2002:1).

The Human Sciences Research Council (2002:5) stated that HIV is a generalised epidemic in South Africa that extends to all age groups, geographic areas, and race groups. Klein (1998:7) confers that HIV/AIDS has an impact on people of all races, cultures, and ethnic groups and that it is believed that 8000 people a day are newly infected with HIV.

It is estimated in the antenatal survey by The Human Science Research Council (2002) that the HIV prevalence in the population of South Africa is 11.4%. This study also observed that 15.2% of persons in the age group of 15 – 49 were HIV positive. The survey, however, did not assess the following groups: children younger than two years old who may have been infected through mother to child transmission (estimated at 83 500), as well as persons living in institutions such as prisons, military barracks and boarding schools (Human Sciences Research Council, 2002:5).

According to existing data from the 2002 antenatal survey, the age group with the highest prevalence was women between the age 25 – 29 (28%), followed by the 30 – 34 (24%) age group. The estimated HIV prevalence among children aged 2 – 14 years of 5.6% was higher than expected (The Human Sciences Research Council, 2002:5).

According to the HIV/AIDS case studies in South Africa (2002a:9), a cumulative total of 13 million children lost their mothers or both parents as a result of AIDS by the year 2000. Some 10.4 million of these children were under the age of fifteen.

Many of the HIV/AIDS orphans are placed in children's home or other places of care. From the researcher's observation and work experience, these children are either cared for by their relatives or taken to an orphanage, hospice or another place of care. However, some relatives have rejected children orphaned by HIV/AIDS because they do not understand how the disease is spread and are afraid of contracting it themselves.

Sanders and Sambo in Overberg (1994:40) observed that one of the most agonising worries of people with AIDS is the fate of their children after they die. On the other hand, these children have to deal with the fact that they lost their parent(s) to this dreadful epidemic and as a result go through many emotions, which could affect their development.

The researcher is of the opinion that the community should be involved in the care and support of HIV/AIDS orphans in conjunction with Non-Governmental Organisations (NGOs) and Community-Based Organisations (CBOs) within an enabling environment, created by government through its policies on childcare. Within an enabling environment, community participation could be realised through the involvement of caregivers who volunteer to take care of HIV/AIDS orphans in various ways, including child-headed households.

The researcher argues that children are the backbone of any country's future and that they hold the key to the success of their respective countries. Respectfully, they need to be loved, cared for and protected from the pain and suffering that goes with the loss of their parents due to HIV/AIDS or other causes. The researcher is of the opinion that children's rights are meant to protect every child, including those children who are infected and affected by HIV/AIDS. These children have not only got the right to be protected, but also to be educated in order to have a brighter future.

The number of HIV/AIDS orphans is overwhelming. Many families are not equipped to deal with these children and as a result, they are shifting the responsibilities to places of care. Placing children in an orphanage and even in a hospice might offer a short term solution to an unprotected child, but can not be a long term sustainable solution for a child that has been orphaned by HIV/AIDS.

Clark (1993:4) commented that hospices have been regarded with scepticism by some health professionals, who see disadvantages in detaching terminal care from other aspects of care, or see specialist provision interposing between mainstream services and their clients.

The researcher's premise for this study is that neither an orphanage (institution, which takes care of HIV/AIDS orphans) nor a hospice is a conducive environment for taking care or looking after HIV/AIDS orphans because these children need more than just care. They need an environment where they will be nurtured, cared for and supported by community members.

This approach is in line with the aim of the social welfare policy, namely to build a self-reliant community, which is equitable, sustainable, accessible, people centred and developmental (White Paper for Social welfare, 1997). Social development, embedded within a developmental model for social welfare, provides a theoretical framework for a community-based approach to HIV/AIDS orphans.

Potgieter (1998:116-119) agrees that the developmental model relies on the active participation of communities on all levels of service planning and delivery and accepts multi-sectoral teamwork as an essential ingredient. Elliott (1993) in Potgieter (1998:116-214) proposes a systems analysis paradigm, along with social development, which embraces holism and comprehensiveness.

Being employed in the National Treasury, the researcher is responsible for policy development and implementation of HIV/AIDS and Employee Assistance Programmes. In this capacity, he is confronted with the realities of the HIV/AIDS pandemic in South Africa on a daily basis and the impact it has on children and in the workplace.

Although all initiatives to care for children who are infected and/or affected by HIV/AIDS need to be applauded, institutional care and hospices, as already indicated, should be seen as a short-term solution for children who are orphaned by HIV/AIDS.

Many of these children are in a position to stay in their parent's homes and head the households themselves provided that older siblings are in a position to do so and/or if caregivers in the community can support them to live independently in the community. Although there are such community-based initiatives as these in operation in South Africa, such as Masoyi Home Based Care and Heartbeat, they are very limited. Research is necessary to determine the success of community-based initiatives such as these so that knowledge and skills on community-based models for the care of HIV/AIDS orphans can be transferred throughout South Africa.

Lewis and Lewis (1989:84) stated that successful programmes build on what is known both about high risk situations and about the resources that enable people to cope with them. Ideally, outreach programmes for vulnerable clients should adhere to the following principles:

- Use whatever sources of support are available, including peers, counsellors, and people who can serve as models of successful coping;
- Give individuals opportunities to help themselves and one another;

- Inform clients about the nature of the new roles or situations they face;
- Assist clients in developing the coping skills they are likely to need in their specific situations; and
- Use methods that enhance clients' sense of control over their situations and their lives.

Lewis and Lewis's principles for an outreach model provide directives for guidelines on community-based care models for HIV/AIDS orphans.

The researcher in this study focused on the Heartbeat's community-based care model where caregivers within the community support and care for children orphaned by HIV/AIDS.

The impact of the environment becomes especially clear when the counsellor works with individuals and groups who have special needs. To help such clients get their needs met, counsellors must become advocates, speaking up on their clients' behalf, intervening actively in the surroundings of the individual or group. The community counsellor works to empower such people (Lewis and Lewis, 1989:14).

In this study, Heartbeat was selected as a case study for the research. Heartbeat is a non-governmental organisation that facilitates change in impoverished communities by alleviating the suffering of the poorest of the poor, with particular reference to children being orphaned mainly as a result of HIV/AIDS. Furthermore, the model focuses on training and development, capacity building, mobilising communities for child care forums, making provision for food parcels for HIV/AIDS orphans and facilitating access to social grants, as well as for lobbying and advocating for the rights of children (Venter, 2004). The rationale to focus the research study on Heartbeat's community-based model is

because the model reflects a comprehensive developmental approach, which encourages community participation, income generation projects, and sustainable development, which is all in line with a developmental approach to social welfare.

Heartbeat functions as a Centre for Community Development, rendering services to HIV/AIDS orphans and children headed households within the community. Lewis and Lewis (1989:13) links the function of the community counsellor with intervention in the environment and thus to effect change in the community. They get involved in community action and work to influence public policy, because there is often no other way to prevent serious mental or physical health problems among their clientele.

Given the impact of the environment on the wellbeing of individual clients, counsellors need to address social and political systems by recognising the problems common to their clients, supporting movement toward healthful change, influencing policy makers, and encouraging positive community action (Lewis and Lewis, 1989:14). One of Heartbeat's roles is to get involved and influence policies, which affect children.

Heartbeat also engages in income generation projects, such as beading and sewing to support HIV/AIDS orphans and poverty-stricken families and therefore implement their community-based care model within a social development framework. The organisation trains and capacitates community members on how to write business proposals and how to run sustainable projects within the community (Venter, 2004). Lewis and Lewis (1989:37) confirm the role of community counsellors and organisations to get involved in education and training of people in life skills and competencies that can help them withstand stress and maintain their mental and physical health. These authors argue that people concerned with primary prevention have come to recognise that programmes can and should focus on the developmental needs of young

children, especially in the areas of social skills and problem solving. In line with this argument, the organisation is involved in the establishment and co-ordination of day care and after school centres, where children are assisted with their homework and life skill's training.

Heartbeat also encourages companies and individuals to participate in the "Sponsor a child in need" project, where individuals could adopt a child or make a monthly contribution towards a child (Venter, 2004).

Heartbeat forms partnerships with existing community-based organisations, non-governmental organisations, the business sector, government, religious organisations and civil society (Venter, 2004). This inter-sectoral approach is in line with the developmental approach to social welfare.

In summary, the intended focus of the research study was to explore the components of community-based care of HIV/AIDS orphans. This study will bring to the attention of stakeholders such as caregivers, government, service providers, and concerned others, the value of and guidelines for participation of communities in the care and support of community-based initiatives for HIV/AIDS orphans.

From these guidelines embedded in a developmental approach to social welfare, stakeholders will be able to identify the challenges for policy formulation for community-based care in order to facilitate an enabling environment for community participation and involvement with children infected and affected by HIV/AIDS.

1.2 PROBLEM FORMULATION

Problem formulation according to Fouché (2002b:104) is primarily aimed at creating a formal, written problem formulation with a view to finalising a research proposal. According to Goddard and Melville (2001:16) the research problem needs to be clear and coherent.

Mouton (2001) in Fouché (2002a:96) stated that people who are more aware of what is going on around them, who are more sensitive to their surroundings, are more likely to come up with interesting topics for research. Most research problems arise from a concrete problem observed in reality.

The researcher has observed in his field of work, the impact that HIV/AIDS has in the community, workplace and the economy of the country. It is thus imperative for the researcher to find ways of helping children who are orphaned by HIV/AIDS.

One of the destructive social impacts of HIV/AIDS is the increasing numbers of parents who die and leave children behind. In South Africa the percentage of children, being orphaned by the AIDS pandemic is on the increase. Many of the HIV/AIDS orphans are not only affected by the death of one or both of their parents, but are also infected themselves, which is an additional trauma to deal with. Both the infected and the affected children are in need of care. There are various options for care available currently, such as orphanages.

Although the White Paper for Social Welfare (1997) supports a community-based approach for children in need within a developmental context, the reality in practice indicates that most children infected and affected by HIV/AIDS are placed in places of institutional care as opposed to community-based care.

Childhood experiences affect a child's development either positively or negatively, and consequently, the outcome of the child's future. It is therefore imperative that the child should get the best of care during the early years of his/her development.

The researcher is of the opinion that an institution taking care of HIV/AIDS orphans is not a conducive environment for a child's development as compared to community-based care, which provides for the involvement and participation of community members as caregivers and supporters. Children growing up in an orphanage do not experience the warmth and protection provided by community-based care facilities within a supportive environment.

The government, in its national guidelines for social services to children infected and affected by HIV/AIDS, stated that the home/community-based care and support strategy developed by the Department of Social Development, is based on the premises that children are better protected when cared for in the context of their communities (Department of Social Development, 2002b).

Although there are national guidelines for social services to children infected and affected by HIV/AIDS (Department of Social Development, 2002b), they are not enforced by the Department of Social Development. The researcher strongly ascertains that should these guidelines be legislated and monitored by the Department of Social Development, HIV/AIDS orphans will be cared for and supported by caregivers from a developmental approach. Hence, there is a need to develop a policy to guide, support, and monitor the establishment of community-based care for children infected and affected by HIV/AIDS in order to create an enabling environment for community participation and involvement.

In summary, due to the HIV/AIDS pandemic in South Africa, the need for care for children being orphaned will increase. It was the premise of this research study that community-based care is the more sustainable solution for these children.

However, although there are guidelines for community-based care for children living with and/or who are affected by HIV/AIDS, there is no clear direction with regard to how this should be implemented in practice.

Initiatives such as the Heartbeat model for community-based care need to be investigated in order to determine the respective components that should be in place for the effective implementation of a community-based care model for HIV/AIDS orphans.

1.3 PURPOSE, GOAL AND OBJECTIVES OF THE RESEARCH STUDY

1.3.1 Purpose of research

Fouché (2002b:108) explains that any research endeavour should have a purpose either to explore, describe or to explain. The researcher conducted an exploratory research, which according to Fouché (2002b:109), is conducted to gain insight into a situation, phenomenon, community or individual.

The purpose of this research study was to explore and gain insight into community-based care of HIV/AIDS orphans.

Directed by an exploratory research purpose, the goal and objectives of the study will be succinctly discussed.

1.3.2 Goal of the study

A goal, aim, or purpose, is a broader, more abstract conception of the end toward which effort and ambition is directed. An objective denotes the more concrete, measurable and more speedily attainable conception of such end towards which effort or ambition is directed (Fouché, 2002b:107).

The goal of the study was to explore community-based care of HIV/AIDS orphans in order to provide guidelines for a sustainable community-based model of care for these children.

1.3.3 Objectives of the study

Whilst a goal is the dream, an objective is a step that one has to take realistically within a certain time-span in order to attain a dream (Fouché, 2002b:107).

The objectives of this study were as follows:

- To conceptualise community-based care for the care of HIV/AIDS orphans.
- To determine the directions and limitations with regard to community-based care within the current policy framework for caring for children infected and affected by HIV/AIDS.
- To identify the components of Heartbeat's model for community participation for community-based care of HIV/AIDS orphans.
- To determine the key components for effective community-based care for the care of HIV/AIDS orphans, which could serve as guidelines for a sustainable community-based care model for these children.

1.4 RESEARCH QUESTION

Fouché (2002c:119) mentioned that one of the purposes of qualitative methods is to discover important questions, processes and relationships, and not to test them. She further elaborated that an exploratory study using qualitative methods usually does not have a precisely delimited problem statement or precise hypothesis, as compared to quantitative methods.

Smith (1990:36) argued that the choice of a research problem should be a highly personalised decision, which may involve background, interests, perceived research strengths, aesthetic judgements, and personal commitments.

For purposes of this research study, the researcher has presented a research question, namely:

What are the key components of community-based care for the care of HIV/AIDS orphans?

1.5 RESEARCH APPROACH

There are two well-known and recognized approaches to research, namely the qualitative paradigm and the quantitative paradigm. A quantitative study is defined as an inquiry into a social or human problem, based on testing a theory composed of variables, measured with numbers and analyzed with statistical procedures in order to determine whether the predictive generalizations of the theory hold true (Creswell in Fouché and Delpont, 2002:79).

According to Fouché and Delpont (2002:79) the qualitative paradigm stems from an anti-positivistic, interpretative approach, which is holistic in nature. The main aim of qualitative research is to understand social life and the meaning that people attach to everyday life. It produces descriptive data in the participant's own written or spoken words and involves the identification of the participant's beliefs and values that underlie the phenomena. The qualitative researcher is therefore concerned with the understanding or rather the explanation and the subjective exploration of reality from the perspective of an insider.

The qualitative research paradigm aims mainly to understand social life and the meaning that people attach to everyday life (Fouché and Delpont, 2002:79).

For the purposes of this study, the researcher used a qualitative approach. The researcher in this study wanted to explore the components of community-based care for the care of HIV/AIDS orphans from a literature perspective as well as within the natural or field setting where the Heartbeat's community-based care model is implemented in an attempt to make sense of the meanings that children infected and affected by HIV/AIDS bring to their personal experiences. The data was descriptive, in the participant's own spoken words.

1.6 TYPE OF RESEARCH

Smith (1990:23) discussed the two types of research as applied and basic. He stated that basic research involves the study of the fundamental properties of subjects and their behaviour. Applied research focuses on the usefulness of subjects and their behaviour. He makes the distinction between the fundamental properties of subjects and their behaviour and the usefulness of subjects and their behaviour.

The researcher made use of applied research. The goal of applied research is to provide a solution/s to a problem in practice. The study intended to determine the key factors for community-based care of HIV/AIDS orphans. The focus was on determining these factors, which could then be utilised as guidelines for a community-based care model as a more sustainable alternative to institutions of care for children who are orphaned by HIV/AIDS.

1.7 RESEARCH DESIGN AND METHODOLOGY

1.7.1 Research design

Fouché (2002d:273) discussed the various strategies of enquiry used by qualitative researchers, which differs depending on the purpose of the study, the

nature of the research question, and the skills and resources available to the researcher.

A research design should provide a plan that specifies how the research is going to be executed in such a way that it answers the research question (Durrheim & Lindegger, 1999:30).

The researcher conducted a case study, which is a type of a qualitative research strategy. Durrheim & Lindegger (1999:255) stated that a case study is an intensive investigation of particular individuals, single families, units, organisations, communities, or social policies. Case studies are usually descriptive in nature and provide rich longitudinal information about individuals or particular situations. They have the advantage of allowing new ideas and hypotheses to emerge from careful and detailed observation.

As indicated in 1.1, the case study focused on Heartbeat as an organisation. Caregivers, one volunteer and HIV/AIDS orphans' shared their perception, experiences, successes, and challenges of Heartbeat's community-based care model.

1.7.2 Data collection method

Leedy (1993:139) commented that all data, all factual information, and all human knowledge must ultimately reach the researcher either as words or numbers.

For purposes of this study, the researcher utilised interviews as a qualitative data collection method. According to Greeff (2002:292) interviewing is the predominant mode of data or information collection in qualitative research.

Kvale in Greeff (2002:292) defined qualitative interviews as “attempts to understand the world from the participant's point of view, to unfold the meaning

of people's experiences and to uncover their lived world prior to scientific explanations". Seidman (1998:1) in Greeff (2002:292) affirms that a researcher would utilise an interview because s/he is interested in other people's stories.

Goddard and Melville (2001:49) indicate that an interview involves a one-on-one verbal interaction between the researcher and a respondent. For this research study, the researcher utilised a semi-structured one-to-one interview.

Greeff (2002:298) elaborated that a semi-structured interview is defined as those organised around areas of particular interest, while still allowing considerable flexibility in scope and depth. At the root of a semi-structured interview is an interest in understanding the experience of other people and the meaning they make of that experience. A semi-structured interview is also used to determine individuals' perceptions, opinions, facts and forecasts, and their reactions to initial findings and potential solutions.

Rubin and Rubin (1995) in Greeff (2002:299) mentioned that an interview is built up of three kinds of questions prior to talking to the participants, that is the main questions, probes and follow-up questions.

In this study a semi-structured interview schedule was utilised to assist the researcher to understand the perceptions and experiences of Heartbeat caregivers, volunteer and HIV/AIDS orphans with regard to key components of community-based care of HIV/AIDS orphans.

1.7.3 Data analysis

Data analysis is the process of bringing order, structure and meaning to the mass of collected data. Qualitative data analysis is a search for general statements about relationships among categories of data; it builds grounded theory (De Vos, 2002:339).

Qualitative researchers collect data in the form of written or spoken language, or in the form of observations that are recorded in language and analyse the data by identifying and categorising themes (Durrheim and Lindegger, 1999:42).

Kerlinger, as quoted by De Vos, Fouché and Venter (2002:223) defined data analysis as “the categorising, ordering, manipulating and summarising of data to obtain answers to research questions”. This analysis of data should be in accordance with the purpose of the study.

Mason (1996:107) commented that the impulse to impose some form of organisation and order on the data can seem overwhelming when one is faced with a mass of apparently unconnected notes and scribbling, interview tapes, transcribed conversations, documents, photographs, maps, diagrams, hunches and ideas. She further suggested that at the very least, one is likely to want to organise one’s material physically into different boxes or filing cabinets, or computer files or directories, according to some form of cross-sectional indexing and cataloguing.

The researcher transcribes and analyses interviews while they are still fresh in the mind (Greeff, 2002:305). This author continues to state that the aim of analysis is to look for trends and patterns that reappear and the basis for analysis is transcripts, tapes, notes and memory (Greeff, 2002:318).

As already indicated, the researcher conducted one-on-one interviews with HIV/AIDS orphans; Heartbeat caregivers and one volunteer according to a semi-structured interview.

According to Heartbeat’s child protection policy (2004), it is important for all persons who come into contact with children within the Heartbeat’s model, to be educated on the code of conduct entailed in the policy. The policy further stated that everyone whom the code of conduct applies, should keep the words of

section 28(2) of the Constitution of South Africa (Act 108 of 1996) in mind, which states: “A child’s best interest are of paramount importance in every matter concerning the child”.

To protect the welfare of the children, Anderson (2004) alluded that everyone who comes into contact with children infected and affected by HIV/AIDS, within Heartbeat, has to familiarise him/herself with a policy document which states amongst others, that children should not be left alone in the presence of an outsider and that the questions that need to be posed to them should be screened to ensure that they do not cause any harm to the children. The researcher was therefore requested to sign the child protection policy and by doing so acknowledged to be bound by it while in contact with the children.

Anderson (2004) stated that the use of a tape recorder could have harmful consequences to the already vulnerable children. Anderson (2004) further mentioned that a Heartbeat staff member should be present in the room during the interviews. The researcher identified a staff member well known to the children, briefed her on the research process and then conducted the interviews in her presence to use her as a sound board.

The researcher chose not to make use of a tape recorder; however, he made comprehensive notes during the interviews. The information gathered was organised in different folders, according to a cross-sectional indexing as suggested by Mason (1996:108).

The researcher made use of the following data analyses process as outlined by De Vos (2002:343):

- The researcher captured the interviews by means of comprehensive field notes.

- The researcher retrieved the information gathered during the interviews, which was organised into folders.
- The researcher then went through this information over and over again, to make sense of the subjects' experiences and to become familiar with the data.
- The researcher wrote notes on the manuscript to help him explore the data further.
- The researcher identified categories of meaning that are internally consistent but distinct from one another. To give a descriptive sense of what each section is about Mason (1996:111) refers to headings and sub-headings.
- Following the describing, classifying and interpreting of the data, the researcher represented the data. De Vos (2002:344) calls this "packaging of what was found in text in tabular or figure form". It is thus a visualisation of what was found by the researcher in the research.

1.8 PILOT STUDY

The pilot study is one way in which the prospective researcher can orientate her/himself to the project s/he has in mind (Strydom, 2002b:210). Mouton (2001) in Strydom (2002b:210) mentioned that one of the most common errors in doing research is that no piloting or pre-testing is done.

Bless and Higson-Smith (2000) in Strydom (2002b:211) defined a pilot study as a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate.

The question to be asked in the pilot study is the practicality of the research study. Barnes (1985:86) identified one of the purposes of an exploratory research method, as finding out if the study is feasible. This means that the researcher determines whether s/he could obtain information desired in a certain locale.

There are a number of questions, which a researcher needs to answer to determine feasibility of the study (Barnes, 1985:86):

- Will the proposed study population answer the questions and allow the researcher to participate in the activities?
- Can the selected population answer the questions?
- Are there key persons in the study population who support the study?
- Can the researcher establish rapport and gain the confidence and co-operation of a wide spectrum of people in this population?
- In addition, is the researcher willing to dress and act appropriately to maintain continued access to all segments of the population?

The researcher had a one-on-one interview with the Heartbeat Programme Manager (Venter, 2004) to establish the feasibility of the study and to get approval to conduct the research study in the organisation. The researcher received a formal letter of approval from Heartbeat to conduct the study within the organisation (See annexure 3).

There were no costs incurred by the Heartbeat organisation. The researcher himself covered all costs related to the study.

The researcher piloted the unstructured interview with a caregiver and one HIV/AIDS orphan identified randomly, to assess if the data collection method has been carefully designed according to Greeff (2002:299). These respondents were not included in the main study. No amendments were necessary after the pilot study.

1.9 RESEARCH POPULATION, SAMPLE AND SAMPLING METHOD

Strydom and Venter (2002:198) mentioned that a universe refers to all potential subjects, who possess the attributes in which the researcher is interested. A population, on the other hand, sets boundaries on the study units. It refers to individuals in the universe, who possess specific characteristics.

For this study, the universe is all Heartbeat's projects in South Africa. The researcher focused on Heartbeat's caregivers and the one volunteer based in Atteridgeville, a township outside of Pretoria, who are directly involved in the community-based care model. They report at the head office in Lynnwood Ridge. The Atteridgeville office constituted the population for the study. There are 116 HIV/AIDS orphans, six caregivers, one volunteer and one community development facilitator who are directly involved in the community-based care model in Atteridgeville.

Arkava and Lane (1983) in Strydom and Venter (2002:199) argued that a sample comprises of the elements of a population considered for actual inclusion in the study. Seaberg (1988) in Strydom and Venter (2002:199) defines a sample as a small portion of the total set of objects, events or persons that together comprise the subject of the study. Goddard and Melville (2001:35) concur that the sample must be large enough to correctly represent a population.

The sample representativeness is seen as "that quality of a sample of having the same distribution of characteristics as the population from which it was selected" (Barnes, 1985:87).

There are two broad categories of techniques for selecting a sample, namely probability and non-probability sampling (Strydom & Venter, 2002:203). The researcher used purposive sampling, which is a type of a non-probability sampling. Leedy (1993:200) commented that there is no way of forecasting,

estimating, or guaranteeing that each element in the population will be represented in the sample, in non-probability sample.

Strydom and Venter (2002:207) explained purposive sampling as a sample based on the judgement of the researcher, in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population.

McRoy (1995) in Fouché and Delport (2002:79) mentioned that a qualitative study is concerned with non-statistical methods and that small samples are often purposively selected.

From the 116 HIV/AIDS orphans in Atteridgeville, twenty were purposively selected for the study. The caregivers were requested to assist the researcher to identify HIV/AIDS orphans according to the following criteria:

- Male and female.
- Aged between 12 and 18.
- Where one or both parents died.
- Child headed households with siblings.
- Supported by a caregiver or larger community (e.g. adopted for school fees or part of “Sponsor a child in need” project).

There are six caregivers and one volunteer in the Atteridgeville project, involved in the care of HIV/AIDS orphans and they were all interviewed for the purpose of the research study.

1.10 ETHICAL ISSUES

Rosenthal and Rosnow (1984:170) defined ethics as a system of moral values, by which behaviour is judged, including scientist’s behaviour.

Strydom (2002a:64) discussed the ethical aspects of research. The ethical aspects relevant in this research study were as follows:

1.10.1 Harm to respondents

Strydom (2002a:64) asserts that subjects could be harmed in a physical and/ or emotional manner.

The researcher visited the community-based projects and interviewed the subjects in their natural settings. There were no chances of any physical harm to the respondents. The children re-experienced their losses when they talked about the Heartbeat model and how it has assisted them in their everyday lives. The researcher requested caregivers to visit the children for a day or two after the interview to support them, if necessary. In addition, the researcher informed the children that they could always talk to the social workers and caregivers if they need to do so.

1.10.2 Informed consent

Williams *et al.* (1995) in Strydom (2002a:65) states that obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedure that will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives.

The researcher has written a letter to the Heartbeat management, to request permission to do the research study through the organisation. A formal agreement has been secured and a written consent from Heartbeat management was received (See annexure 3). In addition respondents were asked to sign an informed consent form where they agreed to participate in the research (See

annexure 2). The researcher has also obtained Heartbeat management's permission to submit the findings in the format of a research report and publication.

1.10.3 Deception of respondents

Loewenberg and Dolgoff (1988) in Strydom (2002a:66) describe the deception of subjects as “deliberately misrepresenting the facts in order to make another person believe what is not true, violating the respect to which every person is entitled.”

The researcher did not have any hidden agenda in conducting this study and had no reason to deceive the subjects. A manager at Heartbeat, Mrs Venter, confirmed the need for this kind of research during a personal interview (17 March 2004). The organisation therefore had been involved from the initial stage of the research.

1.10.4 Violation of privacy/anonymity/confidentiality

Singleton *et al.* (1988:454) in Strydom (2002a:69) explained that the right to privacy is the individual's choice to decide when, where, to whom, and to what extent his or her attitudes, beliefs and behaviour will be revealed.

The researcher visited the subjects and conducted the interviews at their convenient places, where the subjects felt more comfortable. The subjects were also assured of confidentiality, as the researcher is also bound by that principle. The researcher also informed the respondents that their names would not be revealed or displayed and that the research report will not publish or identify their names.

1.10.5 Actions and competence of the researcher

Strydom (2002a:69) commented that researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation.

The researcher was competent to undertake this research since he has previously been involved in a research study in the fulfilment of the social work undergraduate qualification and has successfully completed a Master's module on research methodologies.

1.10.6 Debriefing of respondents

Babbie (2001:475) in Strydom (2002a:73) mentioned that through debriefing, problems generated by the research experience could be corrected.

Judd *et al.* (1991:517) in Strydom (2002a:73) concurs that debriefing sessions during which subjects get the opportunity, after the study, to work through their experience and its aftermath, are possibly one way in which the researcher can assist subjects and minimise harm.

The researcher gave the respondents an opportunity to assess the interview process and although no respondent seemed to be affected emotionally, the researcher referred them to the Social worker and/or caregivers if they so needed.

1.11 DEFINITION OF KEY CONCEPTS

The key concepts of the study were as follows:

1.11.1 HIV/AIDS

AIDS is defined as an Acquired Immune Deficiency Syndrome (compare Klein, 1998:7 and Barnett and Whiteside, 2002:28). HIV is the abbreviation for Human Immunodeficiency Virus, which is the virus that causes AIDS (American International AIDS Foundation, 2004). A person with HIV can however, be supported with a healthy life style.

This study focused on orphans who are both infected and affected by HIV/AIDS.

1.11.2 HIV/AIDS Orphans

Barnett and Whiteside (2002:199) defined orphans as “children with mother or both parents missing.”

Koff (1980:35) refers to orphans as children who have lost both parents to HIV/AIDS. Uys and Cameron (2003:174) take a wider stance in defining an orphan, namely as a child under the age of fifteen, who has lost his or her mother.

For purpose of this research, HIV/AIDS orphans refer to children with either no parents due to AIDS or left by one or both parents to care for themselves, because the parent(s) is sick from HIV/AIDS him/herself. The HIV/AIDS orphans referred to in this study might be infected by HIV/AIDS themselves and therefore reference is made to orphans infected and affected by HIV/AIDS.

1.11.3 Community-based care

The Department of Social Development (2002c) referred to community-based care as a support system which enables the individual, the family and the community to have access to services nearest to home. Lewis and Lewis (1989:7) referred to it as a system of interdependent persons, groups and organisations that meet individual's primary needs; affects his/her life and mediates between him/her and the society.

For this study, community-based care is referred to as the care and support of HIV/AIDS orphans in the comfort of their homes with the help of different partners/stakeholders in the community.

1.12 LIMITATIONS OF THE STUDY

The researcher requested the caregivers to assist in the identification of HIV/AIDS orphans according to the following criteria:

- Male and female.
- Aged between 12 and 18.
- Where one or both parents died.
- Child headed households with siblings.
- Supported by a caregiver or larger community (e.g. adopted for school fees or part of "Sponsor a child in need" project).

It is possible that the caregivers could have included HIV/AIDS orphans whom they liked without using the criteria as mentioned above.

As indicated in this chapter, the interviews were conducted in the presence of Heartbeat's community development facilitator in compliance with Heartbeat's child protection policy (2004). This could have influenced the respondents to

give what they perceived to be the desired answers and holding back information that could have been important for the research study.

1.13 CONTENTS OF RESEARCH REPORT

Chapter 1

In this chapter, the researcher contextualised the research topic, formulated the research problem, goals and objectives, the research question; research methodology and limitations of the study.

Chapter 2

The researcher provides a theoretical framework on the impact of HIV/AIDS on children, developmental social welfare for the care of HIV/AIDS orphans, institutionalisation versus community-based care and Heartbeat's community-based care model.

Chapter 3

This chapter focuses on the research methodology and it presents the research findings of the empirical study and the analysis of the research findings.

Chapter 4

The last chapter summarises the study with relevant conclusions and recommendations.

Chapter 2

COMMUNITY-BASED CARE FOR HIV/AIDS ORPHANS: A THEORETICAL PERSPECTIVE

2.1 INTRODUCTION

Many children have been orphaned by HIV/AIDS and some of these children are severely affected by this pandemic. These children need a nurturing environment to grow and develop. The Centre for Policy Studies (2001:13) warned that crime levels will rise sharply in the next twenty years as HIV/AIDS orphans increased. The Centre further commented that one of the major concerns, if the Government does not deal with HIV/AIDS orphans, is the social unrest and instability this will generate; particularly in areas where crime levels are already high and street children and displaced small people are already common.

In South Africa, policies were adopted such as the White Paper for Social Welfare (1997), the Financing Policy for Developmental Social Services (1999), and the National Guidelines for Social Services to Children Infected and Affected by HIV/AIDS (2002) to enhance and facilitate community based care, even though the implementation of these policies are not well monitored. However, there are examples such as Heartbeat, an NGO caring for HIV/AIDS orphans, who has developed and implemented a community-based care model. As indicated in Chapter 1, Heartbeat was used as a case study for this research study and will therefore form part of the discussion in this chapter.

As mentioned above, the implementation of these policies are not well monitored by the Government and this poses a challenge to Government, Non-Governmental Organisations, Community-Based Organisations, Health and other professionals and volunteers to fully participate in the care and support of HIV/AIDS orphans. It is against this background that the researcher intended to

explore the components of community-based care in the care of HIV/AIDS orphans in order to provide guidelines for a sustainable community-based model of care for these children.

In this chapter the focus will be on community-based care as opposed to institutionalisation of children, a brief overview of the policy framework for the care of HIV/AIDS orphans within a developmental framework, the rights and needs of children infected and affected by HIV/AIDS and the impact of HIV/AIDS on children. Finally, community-based care as a model, with special reference to the Heartbeat's community-based care model as integrated with the literature review on the key components for community-based care of these children will be discussed.

2.2 THE IMPACT OF HIV/AIDS ON CHILDREN

The HIV/AIDS pandemic has impacted greatly on the community and most especially on children. Death of a parent affects the household income, family stability and the economy of the country. Consequently it affects children, as they leave school, are left homeless and to fend for themselves.

As indicated in Chapter 1, AIDS or Acquired Immune Deficiency Syndrome is a disease caused by the human immune deficiency virus (HIV), which destroys the body's natural ability to fight illness. Diseases such as pneumonia and rare cancers develop as the virus causes a breakdown in the body's immune system. One or more of these diseases actually cause death.

The AIDS pandemic was first recognised in Africa in 1983 when clinicians in Europe reported the first cases among African patients (Sanders and Sambo in Overberg, 1994:40). The pandemic leads to death which causes grief as explained by Klein (1998:29) who stated that, more often than not, the grief in

AIDS survivors incorporates anger, fear, rage, and numbness to a greater extent than that seen in grief not associated with HIV/AIDS-related deaths.

In the following sub-section, the facts and statistics on HIV/AIDS will be presented and indicated how it affects children orphaned by this pandemic.

2.2.1. Facts about HIV/AIDS

According to Uys and Cameron (2003:174), in 2001, UNAIDS released the following facts regarding children and HIV/AIDS:

- HIV/AIDS has orphaned at least 13 million children currently less than fifteen years of age. The total number of children orphaned by the pandemic since it began is forecast to almost double to 25 million by 2010.
- AIDS-related deaths caused some 2.3 million children to become orphans in 2000 (one every fourteen seconds!). UNICEF estimates that up to a third of these children were less than five years old (Uys and Cameron, 2003:174).
- An estimated 10.3 million people aged fifteen to twenty-four are living with HIV/AIDS, and a half of all new infections, over 7000 daily, are occurring among young people.
- In some of the worst-affected countries, adolescent girls are being infected at a rate five to six times higher than are boys.

HIV/AIDS is eroding precious and hard-won infant and child survival gains. In the world's nine most severely affected countries (all of them located in Africa), where at least one-tenth of the adult population has HIV, life expectancy for a child born in 2000 to 2005 will drop to forty-three from the pre-AIDS expectancy of sixty years of life (Uys and Cameron, 2003:174).

In most parts of the industrialised world usually no more than one per cent of the child population is orphaned. Before the onset of HIV/AIDS, societies in the developing world absorbed orphans into extended families and communities at a rate of just over two per cent of the child population (between two and five per cent in South Africa), and traditionally orphanhood was not perceived to be a problem (Uys and Cameron, 2003:175). Today, because of HIV/AIDS, the situation is vastly different.

Uys and Cameron (2003:176) continue by saying that orphans and affected children are even more vulnerable than adults, as they face the possibility of stigma relating to their own status if they are infected, as well as from the stigma flowing from their parent's or caregiver's status.

As discussed in Chapter 1, Barnett and Whiteside (2002:199) defined orphans as "children with mother or both parents missing." Koff (1980:35) refers to orphans as children who have lost both parents to HIV/AIDS whereas Uys and Cameron (2003:174) define an orphan as a child under the age of fifteen, who has lost his or her mother. Clearly, HIV/AIDS orphans are traumatised by these losses and whilst they have to deal with the trauma, they have to face many other challenges such as housing, poverty and survival.

Youth and children are amongst the priority groups, which the South African Government refers to as vulnerable groups. These are groups of people who must be given top priority in any service delivery that is available, including health related problems (Mamasela, 1998:65).

The researcher has observed in his working experience regarding HIV/AIDS that children who lost either one or both their parents, due to illness or death are either taken to places of care, left in the care of their relatives, as granny-headed families or by themselves, as child-headed families. Uys and Cameron (2003:177) termed this "parentification", which refers to the process of creating a

parent out of a child in order to care for a parent or siblings. This arrangement breaks the family system which existed before these unfortunate incidences.

2.2.2 Children's grief and stress due to HIV/AIDS

The consequences of children experiencing HIV/AIDS grief could be devastating. Wells (1993:1) commented that emotional bereavement in a child goes as deep as it does for an adult.

Thoburn (1994:148) sensitised that people must always remember that for a child to lose parents and siblings is also to lose grandparents, aunts and uncles for that future adult's children. However, there are parents who have not made too good a job of parenting their own youngsters, but whose support as grandparents has played an important part in helping a next generation family to stay together.

The researcher in his work context observed that the reality of HIV/AIDS in the family is that children are now caring for the sick and assuming adult responsibilities before they are ready to do so. Children are leaving school earlier; they marry earlier, enter the labour force earlier, and are frequently sexually exploited. Legislation is there to protect these children as discussed earlier, but people and institutions with delegated authority are not doing enough to protect these children.

Lewis and Lewis (1989:103) discussed a crisis as a temporary stage in a person's life when his or her normal ways of dealing with the world are suddenly interrupted. The researcher asserts that children, who have lost one or both parents, need support to deal with their loss. Often people in a crisis also need personal support and encouragement to cope with their feelings of helplessness or frustration (Lewis and Lewis, 1989:103).

Children, who are faced with a crisis of losing a parent, need help from professionals in exploring their immediate problem, finding resources that will enable them to solve the problem, and developing a practical plan of action. Although a crisis is temporary, the way that it is handled could have long-lasting damage. It is therefore important that children who lost their parents be assessed and attended to immediately by a professional, to avoid a long-lasting negative impact.

Uys and Cameron (2003:177) assert that when the extended family either does not exist or simply cannot cope, the only alternative is often for siblings to live together, frequently with no adult supervision. Child-headed households have their own unique problems, which include:

- Poverty.
- Lack of supervision and care.
- Stunting and hunger.
- Educational failure.
- Lack of adequate medical care.
- Psychological problems.
- Disruption of normal childhood and adolescence.
- Exploitation.
- Early marriage.
- Discrimination.
- Poor housing.
- Child labour.

Garnezy and Rutter (1983) in Sharp and Cowie (1998:21) categorised other sources of stress for these children as, amongst others:

- Loss.
- Events that change the family status quo.

- Events which require social adaptation.
- Acute negative events such as trauma.
- Death of a close family member.

The stressors mentioned above could result in a Post Traumatic Stress Disorder, if left unattended. These children could experience depression, anxiety, truancy, drug and alcohol abuse, helplessness, rebellious and antisocial behaviour, suicidal thoughts and behaviour (Sharp and Cowie, 1998:28).

Lewis and Lewis (1989:13) confirm that a stressful situation can trigger a variety of physical, psychological, and social dysfunctions, though the stress reaction, in itself, is transient.

All children have physical, emotional, social, and intellectual needs that must be met if they are to enjoy life, develop their full potential, and develop into participating, contributing adults (Uys and Cameron, 2003:180).

Health professionals know that people facing difficult situations need to develop new and practical problem-solving strategies and approaches to everyday living. They also know that such people need close contact with others and should be linked to people who can provide support and encouragement (Lewis and Lewis, 1989:13).

Following from the above discussion, key areas on the impact of HIV/AIDS on children, could be summarised as:

- Grief and stress.
- Child neglect and abuse, which exposes these children to more vulnerability.
- Lack of physical and emotional support from the government and the community.

Children orphaned by HIV/AIDS can be cared for in various ways, either in institutions for children too young to take care of themselves or who are too ill or terminal due to the pandemic or in various types of community-based settings such as the family and relatives within the community. However, the choice of placement has severe implications for children infected and affected by HIV/AIDS as alluded to in this chapter.

Community-based care models are in line with the South African welfare policy (White Paper for Social Welfare, 1997) as will next be briefly outlined.

2.3 DEVELOPMENTAL SOCIAL WELFARE FOR THE CARE OF HIV/AIDS ORPHANS

It was mentioned earlier in this chapter that the South African government has adopted legislation and guidelines for the care and support of children infected and affected by HIV/AIDS. The Department of Social Development is thus custodian of the implementation and monitoring of these legislative frameworks and guiding principles however, it lacks an effective monitoring and evaluation system to ensure compliance.

The vision of the National Developmental Social Welfare strategy in the White Paper for Social Welfare (1997) is a welfare system, which facilitates the development of human capacity and self-reliance within a caring and enabling socio-economic environment. The mission is to serve and build a self-reliant nation in partnership with all stakeholders through an integrated social welfare system, which maximises its existing potential and which is equitable, sustainable, accessible, people-centred and developmental.

The mission of the social welfare strategy mentioned above is in line with the social developmental approach, which according to Midgley (1997:180) shares similar commitments of promoting and enhancing human welfare with the social

work approach, but it has its own distinctive features. It uses development as a means of enhancing people's welfare, which entails social intervention and economic development. It requires that economic development should result in tangible improvements in social well-being for everyone, and that social programmes contribute to economic development.

Lombard (1996:163) argued that strategies for implementing social development link the residual-institutional models of social welfare to a developmental model and that a social developmental approach is inclusive of helping individuals, groups and communities in a different manner such as to develop human resources (including capacity building) and, where possible, facilitate and enhance economic development. It is based on this principle that the researcher argues the relevance of a community-based model in helping children who are infected and affected by HIV/AIDS.

The developmental model incorporates the social development approach and therefore links social and economic policies. Social programmes that promote productive employment or self-employment are given special emphasis in the developmental approach. Social development however, is based on the principle of human dignity, equality and social justice arrived at by achieving an integrated, balanced and unified advanced society. It also involves building bridges and networks for people to participate in society in different ways, such as the involvement in labour markets. The approaches also address social problems from a preventative perspective and approach individuals, families and communities from an empowerment, strengths perspective.

Midgley (2001:247) concurs that developmental welfare is concerned not only with increasing labour-market participation among welfare clients but with a variety of interventions that foster economic participation and raise standards of living.

Potgieter (1998:116-119) adds that the developmental approach assumes that services and programmes should be developed to solve problems connected with the unmet needs of people. He argues that the developmental approach not only aims to prevent social problems but also ensures equality in the distribution of resources and reduces inequality in the provision of services.

The Department of Social Development on its HIV/AIDS programme for 2003/2004 (2002) stated that in caring for those infected and affected by HIV/AIDS, it will roll out a community-based care and support programme; protection measures and services for HIV/AIDS orphans and vulnerable children; capacity building skills and the establishment of partnerships. The researcher acknowledges the efforts by this Department to develop and roll out these programmes, but is concerned about the rate that the programmes are implemented.

As referred to earlier, during 2002, the Department of Social Development has drafted National Guidelines for Social Services to Children infected and affected by HIV/AIDS, and community-based care and support programmes are embedded in these guidelines, which, a brief reference will be made to, are not well monitored for implementation.

In the following sub-sections the policy issues and the rights and needs of children infected and affected by HIV/AIDS and their support systems will be discussed.

2.3.1 Policy issues

Historically, blacks were disadvantaged in South Africa and they did not benefit from government policies. Post 1994, the South Africa government adopted the Reconstruction and Development Programme policy framework (1994:74) as drafted by the African National Congress, which stipulates that the needs of

children must be paramount throughout all programmes aimed at meeting basic needs and socio-economic upliftment and to redress the wrongs of the past.

Over 5.5 million children are benefiting from the social grants, which is given to vulnerable children including those orphaned by HIV/AIDS (Department of Social Development, 2005). The researcher acknowledges that the Government has drafted policies; legislature and guidelines to protect children infected and affected by HIV/AIDS, but asserts that government has failed these children by not providing evaluation and monitoring systems to ensure that organisations implementing these programmes are in line with the vision and mission of the developmental social welfare strategy.

The researcher is of the opinion that people, NGOs and CBOs should not rely on the government for handouts, but should rather engage in income-generating projects which will sustain them beyond government grants. Garmezy (1992:46) stated that South African laws have given a promise of equality, but their fulfilment has lagged. In terms of economic status, a large portion of the black population is disadvantaged, and its consequences for the health of black infants provide a discouraging picture. It is against this background that the researcher is of the opinion that the government is neglecting its responsibility of looking after the disadvantaged children, most especially HIV/AIDS orphans.

The Government is on track in addressing the question of a welfare state. The government's aim in the White Paper for Social welfare (1997) is to build a self-reliant community, which is equitable, sustainable, accessible, people centred and developmental and that social development, embedded within a developmental model for social welfare, provides a theoretical framework for a community-based approach to HIV/AIDS orphans. The Government went to as far as developing a policy, which will complement the White Paper regarding the financing of social welfare services. The Financing Policy for Developmental Social Services (1999) also supports a developmental perspective as it aims to

serve and build a self-reliant nation in partnership with all stakeholders through an integrated social welfare system, which maximise its existing potential and which is equitable, sustainable, accessible, people-centred and developmental.

The government provides support to NGOs advocating for children infected and affected by HIV/AIDS through funding. Heartbeat is one such organisation. These organisations are required to submit reports to the Department of Social Development for accountability of these funds as stipulated in the Financing Policy for Developmental Social Services (1999). As mentioned earlier, there are however, no policies in place to regulate, monitor and evaluate these organisations in the implementation of the community-based care model.

2.3.2 Rights and needs of children infected and affected by HIV/AIDS

The lobbying for children's rights is diverse and includes politicians, policy makers and professionals involved in the education and care of children. Their common belief is that the condition of children will not be improved unless they have legally and politically supported rights, conferred upon them directly and backed by adequate resources (Kay, 2001:15).

Children like any other citizen of South Africa are protected by the South African Constitution (Act 108 of 1996), though they are specially protected by the children's rights, as will be discussed in this chapter. It should however be noted that with rights come responsibility and that children from any early age should be taught responsibility (Sharp and Cowie, 1998:3).

The United Nations Convention on the rights of the child (1991) issued a statement of principles about the way in which children should be treated and how their welfare should be promoted. The underpinning values of the Convention include the belief that children have equal rights to adults and that adults have a responsibility to ensure that children's rights and welfare are

safeguarded and promoted. Children depend on adults for their care and safety and this dependent status makes them vulnerable (Kay, 2001:13).

Sharp and Cowie (1998:5) make reference to the children's rights as categorised by the Children's Rights Development Unit (1993:6). The three categories are:

- Protection: Children have the right to be protected from abuse, torture and armed conflict.
- Provision: Children have a provision of the right to life, state care, education, health services and social security.
- Participation: Children have the right to participate in decision-making on matters affecting them, with due consideration for the age and maturity of the child; in judicial and administrative proceedings affecting the child, either directly or through a representative.

Sharp and Cowie (1998:2) highlighted that children have certain needs, and that if those needs are not met, then normal social, emotional and cognitive developmental processes are put at risk. Kay (2001:14) mentioned that many of the principles of children's rights have gradually developed from increasing knowledge and understanding of the vulnerability of children and the abuses and hardships they suffer from. Every day, thousands of children across the world die of starvation, are subject to abuse and neglect, lack parents, warmth, shelter, love and even basic care. To counteract this affect, the needs of children should be of paramount importance in planning for community-based care.

The basic needs of children infected and affected by HIV/AIDS are not different from those of other children. However, these needs are more intensified due to the vulnerability of the children (Compare Sharp & Cowie, 1998:3; Coleman & Warren-Adamson, 1992 and Kay, 2001:116):

- Basic physical care: Children need to be assured of warmth, shelter, food and rest; they need to be kept clean.
- Protection: Children need to be kept safe and to be protected from danger, including the risk of sexual abuse or physical violence.
- Security, guidance, support and control: Children need to have a sense of continuity of care and the expectation that the family unit will remain stable. Routines and predictable patterns of care, reasonable sets of rules and consistent monitoring facilitate this sense of security. They need to be in a context where there is consistent, firm guidance on acceptable social behaviour, and where adults act as role models for these children.
- Emotional security: Including harmony, stability and continuity of care, routines and predictability in daily care, consistency in style and approach of care, and lack of anxiety.
- Methods of discipline: These methods should be suitable to the child's age and understanding and should not be cruel and humiliating to the child.
- Love, affection and respect: Children need to have affectionate, respectful physical contact, to be comforted when in distress, to be held with tenderness; to be listened to; to be taken seriously; to be given opportunities for challenge, exploration and the growth of a sense of competence; to be encouraged to share feelings, including those that express anger, bewilderment and hurt.
- Stimulation to learn and access to schooling: Children need to explore their world at their own pace and they need to have access to appropriate educational opportunities in contexts, where there is a concern to provide them with resources to help them learn and realise their potential.

- Autonomy and responsibility: Children and young people need to gain the experience of taking responsibility for themselves and others according to age-appropriate ways such as tidying, helping with household chores and managing their pocket money. They need to be given helpful information on sexual matters, to help them make informed, reasoned decisions, which affect themselves, their families and friends. There should be opportunities to deal with ethical dilemmas and interpersonal conflicts and to live with the consequences, whatever these may be.

Uys and Cameron (2003:182) cautioned that in order for caregivers to meet the basic needs of children infected and affected by HIV/AIDS in their care, they need access, at the very least, to functioning health, education, and social services.

The fulfilments of children's needs are of paramount importance, irrespective of whether they are placed in a place of safety or within their communities. For HIV/AIDS orphans to grow and develop mentally, physically, emotionally and psychologically, it is imperative that these needs are met. The premise of a community-based care model is that these needs could more easily be met if a child is placed within a family context.

2.3.3 Support system for children infected and affected by HIV/AIDS

The family plays an important role in the upbringing and socialisation of a child from an early age. Sharp and Cowie (1998:11) stated that the early years lay a strong foundation for later emotional development and many of the difficulties experienced by children later on can be traced back to the first relationships with primary caregivers.

The United Nations Convention (1991) states in its preamble: "The family, as the fundamental group in society and the natural environment for the growth and

well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community” (Sharp and Cowie, 1998:7).

The focus on the family is also emphasised by the White Paper for Social Welfare (1997), which states that the objective of social development is to bring about sustained improvement in the well-being of the individual, family, community and the society at large.

The family, as a system, is one of the most basic units of support in society. People normally find their own support system in families, relatives, churches, friends and significant others. The researcher argues that a support system is even more crucial in instances where HIV/AIDS orphans have no families to support them.

McWhirter, McWhirter, McWhirter and McWhirter (1998:43) explained that the family is a natural system consisting of connected components (family members) that are organised around various interactional functions. Amongst those functions are giving and receiving affection, child rearing, and the division of labour. As families live together from day to day, they develop systematic patterns of behaviour that serve to maintain the system in a state of equilibrium. Each family member contributes to this equilibrium or homeostatic balance.

The researcher agrees with McWhirter *et al.* (1998) that a family is an integral part of each member within the system and that an alteration or change in the system can bring enormous stress and dysfunction in particular to a child’s life.

Uys and Cameron (2003:176) comment that for generations, the family as a system has met most of the basic needs of children and provided a protective social environment in which they could grow and develop. At a time when the family is most needed as a support system for HIV/AIDS orphans and affected

children, the stigma associated with HIV/AIDS is further affecting the willingness of families to care for and support these children. This is resulting in increased child mobility and the exploitation and neglect of children.

These children should therefore be taken care of by a system they are more comfortable with and attached to such as their immediate family or their community. Herbert (1993:35) asserts that any individual in a family system is affected by the activities of other members of the family, activities which his or her actions or decisions, in turn, influence.

Uys and Cameron (2003:181) observed that there is general consensus that interventions to assist HIV/AIDS orphans and affected children should be based in, and owned by, the affected communities themselves.

Children who have lost one or both their parents are exposed to high levels of distress, especially if there is no adult supervision or some kind of social support. The researcher is of the opinion that these children should be placed within the community under the supervision of an adult, family member, relative or an older child in cases where the HIV/AIDS orphans do not have family members, as long as it is in an environment more familiar to the child. The reasons behind this argument will suffice in the next discussion.

2.4 INSTITUTIONALISATION VERSUS COMMUNITY-BASED CARE

There are two main options for care of children infected and affected by HIV/AIDS, namely institutions and community-based options.

2.4.1 Institutions

According to Rivlin and Wolfe (1985:204) one of the goals of institutions preclude the treatment of children as people. In these settings little space or time belongs to the child.

The concept of institutionalisation refers to a caring system, not cure-oriented, with services provided by a comprehensive team of practitioners. It is both a response to the existing status of health care as well as a stimulus to assist the health care system to respond to changing societal values of humanism, free choice, and consumerism (Koff, 1980:5).

Rivlin and Wolfe (1985:109) stated that there are two types of institutionalisation namely, partial and total institution, which the distinction between the two is not entirely clear. It would seem that in partial institution children are placed for a short period of time as compared to total institution where their placement is more permanent. The degree of control in these institutions differs slightly.

There are concerns with regard to institutionalisation, which include the structuring of the day, the routine of time and activities, and the narrow definition of goals, which provide children with little opportunity for serendipity (Rivlin Wolfe, 1985:207).

From the concerns raised by Rivlin and Wolfe, the researcher has also observed in his working context that in institutions, there are structures in all aspects of the children's daily lives which include the physical setting, activities, and the time frame within which they occur. They are required to wake up, eat meals, and go to sleep at set times each day all week whether or not the scheduling meets their needs.

Rivlin and Wolfe (1985:107) commented that institutionalisation emphasise and provoke deviance as opposed to eliminating it. The institution itself, through the imposition of order, its mechanism of social control, drugs, punishment, and isolation, is more akin to its predecessors than most would admit. The understanding that the goal of the institution is to socialise children to return to their communities is contradicted in several ways as most of them do not return to their families.

Thoburn (1994:149) stated that child placement is a costly enterprise in terms of the emotional energy of all those involved, as well as of finances and professional time. And so it should be.

The researcher is of an opinion that children, as the future of every society, and children at risk of permanent separation from their families need the care and protection of the government and their respective communities. Caring for these children in the communities will save the government a lot of money in terms of costs for building infrastructures and employing professionals and specialists to take care of them in institutions on a permanent basis. However, this does not negate government's responsibility to contribute financially and in other ways to community-based care initiatives. The government has registered 1.9 million children under the age of eleven for social grants, 100 000 more than the set target of 1.8 million (The Department of Social Development, 2005). This goes to show that government is contributing towards the welfare of vulnerable children including those infected and affected by HIV/AIDS.

Rivlin and Wolfe (1985:107) in their concern about institutionalisation, state that children remain institutionalised for many years before their final release, occurring mainly when they reach maximum age. These authors question what these children are socialised to. The institution and its socio-physical environment support the very behaviour for which children were supposedly institutionalised for in the first place. This system, and the adults who implement

its principles, has an incredible amount of control over the daily and yearly lives of these children. That power is virtually absolute and unquestionable.

However, children, according to Kay (2001:85) can never be made absolutely free. Every part of living has some risks attached to it and efforts to eradicate all physical risks to the child could result in creating such a stifling environment that the child is in danger of suffering from complete lack of stimulation. Children are gradually losing access to a world of free play which is “owned” and controlled by children, and in which older children develop responsibility through caring for younger children.

Rivlin and Wolfe (1985:204) agree that when time is called “free”, limits on movement and resources circumscribe what can be done. They argue however, that even this limited freedom is granted as a privilege. The use of the environment, its aesthetics, and its accessibility are controlled by adults.

Children placed in institutions are almost completely cut off from their homes and communities. Every aspect of their daily lives is controlled by adults, rules and regulations governing these institutions. Children in these settings have little chance of seeing alternative ways of living and have little or no power to make changes of any kind. The researcher would therefore argue that if institutionalisation is unavoidable, there should be a stipulated time limit for the placement of HIV/AIDS orphans in institutions, to avoid the permanence syndrome.

The researcher strongly agrees with the fact that placing children in institutions affects the child’s stimulation drastically. Although institutionalisation is used to protect children from vulnerability such as abuse, neglect, poverty and harm, it could never be the best option for children who can stay within the family in the community, where organisations such as Heartbeat could care and support them. Removing HIV/AIDS orphans from their communities therefore, should not be

considered as one of the alternatives in caring for these children without exploring the possibility of community-based care.

Placements in institutions could only be considered for HIV/AIDS orphans whose special needs cannot be met or provided for by their families. However, this should be considered only after all the possible avenues have been exhausted, including home-based care. Institutionalisation for HIV/AIDS orphans who have no immediate families or shelter where they could be looked after should thus be the last option. This kind of arrangement however, should only be temporary; until the child is old enough to be reintegrated back into the community such as child-headed households under the supervision of a caregiver.

In summary, the researcher agrees with Uys and Cameron (2003:182), who affirm that placing children in institutions is not generally the most appropriate intervention for HIV/AIDS orphans and affected children as they can fail to meet children's developmental and emotional needs. While institutionalisation may be the only option for some children, in general it is more sustainable to devote resources towards strengthening the abilities of families and communities to care for orphaned and affected children.

From the above discussion it is clear that institutionalisation of a child infected and affected by HIV/AIDS poses specific concerns. Due to the grief and stress related to the HIV/AIDS the children need the support from significant people in their lives within the community, even if they are institutionalised. It is within this context that community-based care for children infected and affected by HIV/AIDS seems to be a better option for these children.

2.4.2 Community-based care

As indicated in Chapter 1, the Department of Social Development in its National Guidelines for social services to children infected and affected by HIV/AIDS

(2002b) defined community-based care as a support system which enables the individual, the family and the community to have access to services nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and strengthens mutual aid opportunities and social responsibility.

Uys and Cameron (2003:1) indicated that as early as 1986, the Committee on a National strategy for AIDS (CNSA) for the USA described community-based care as care occurring at a patient's residence to supplement or replace hospital-based care.

Lewis and Lewis (1989:7) defined community-based care as a system of interdependent persons, groups, and organizations that:

- Meet the individual's primary needs.
- Affects the individual's life.
- Mediates between the individual and society as whole.

Heginbotham (1990:47) refers to community care as a comprehensive arrangement of community health and social care dovetailed together in such a way as to provide as seamless a service as possible. Heginbotham (1990:47) further argued that good community care will bring together those aspects of local helping services, which complement social care in a co-ordinated and collaborative way.

The researcher identifies more with Heginbotham's (1990) definition, which looks at community-based care as a comprehensive arrangement of social care and community health.

A community-based care model should provide the kind of support system that HIV/AIDS orphans could have received from their parents. Uys and Cameron

(2003:182) stated that family and community-based approaches appear to best meet the child's need for security and socialisation; however they need to be supported and strengthened if they are to remain a viable way of meeting all the needs of the child.

Making reference to community-based care (McWhirter *et al.* 1993:224) indicate that for young people, this means learning how their lives are influenced by family, school, and the larger society, developing the skills to combat negative influences and make positive choices for their lives, and supporting the healthy choices of other young people in their families, schools, and communities.

Kay (2001:18) refers to the relationship between caregivers and children within a community-based care approach and argues that there are a number of different aspects of interaction between caregivers and children, which has an influence on their development. The most important dimensions of interaction are:

- Warmth (caring and expressing affection for the child).
- Responsiveness (tuning in to the child's needs, wants, moods and problems and responding to them).
- Methods of control (to reduce the incidence of unwanted behaviour).
- Communication (listening to children's views, opinions and needs).

Thoburn (1994:73) argues that there is no doubt that a youngster's need for stability and security, together with his or her need for a sense of personal identity, can best be met by returning permanently to live with both or at least one natural parent or caring family member, provided that they can provide "good enough" care, either alone, or with continued help.

Lewis and Lewis (1989:7) state that community-based care as a system means that it has unity and continuity. The individuals, groups, and organisations making

up a community are interdependent, meaning that they are all linked, both affecting and being affected by one another.

Lewis and Lewis (1989:82) further stated that community-based care helps people to solve their problems, increasing both their sense of control and their confidence; confident people are more likely to have strong social support systems and to apply their problem-solving skills effectively.

Wetherington and Kessler (1991) in Sharp and Cowie (1998:14) noted that not only is the actual availability of community support protective but also the belief that others are available to provide emotional support. They found that people who believed that others would support them were more resistant to psychological distress.

Whether individuals are able to withstand a high degree of stress depends, at least in part, on factors that can serve as buffers to protect the individual's sense of wellbeing. Such buffers include community support systems (Lewis and Lewis, 1989:13).

Where the family can not provide any buffers for HIV/AIDS orphans, the community, through models like Heartbeat's, could serve as support systems. These systems can provide care, support and even shelter for children infected and affected by HIV/AIDS.

Members of the community are in the best position to know which households are most severely affected and what sort of help is appropriate. They know who is dying, who has died, who has been taken in by relatives, who is living alone, and who has enough to eat (Uys and Cameron, 2003:181).

Community-based care incorporates the communities help in identifying HIV/AIDS orphans, provision of the basic day-to-day needs of the children as

well as emotional support. The community should support both the children and their caregivers as well as act as a forum for lobbying authorities to assist in providing an effective response to the needs and requests of HIV/AIDS orphans and the caregivers.

Community-based care also includes support by professionals as was highlighted in a conference organised by The Departments of Social Development and Health and other stakeholders as a response to a call for co-ordinated action for children affected by HIV/AIDS (2002a). One of the recommendations was to initiate a process for identifying vulnerable children using sources such as local police stations, churches, medical centres, schools, tribal authorities and early childhood centres.

Kay (2001:134) emphasises the partnership between professionals and community members involved in community-based care, stating that the relationship could be stressful if it is unclear what is expected in the partnership or in instances where there are role conflicts (Kay, 2001:134).

Heginbotham (1990:52) concurs that community care requires care within the community, undertaken by a range of agencies, statutory, voluntary and private, as a way of assisting and supporting vulnerable and disadvantaged people.

Lewis and Lewis (1989:67) made special reference to the involvement of schools and teachers in the care and support of children infected and affected by HIV/AIDS, which allow children to be reached efficiently at the ages most appropriate for learning particular skills. School-focused programmes are aimed at a broad range of young people who have not necessarily exhibited problems whilst these programmes simultaneously help to exemplify the focus on competency building and health promotion.

2.4.2.1 Principles, strategies and criteria for community-based care of HIV/AIDS orphans

Uys and Cameron (2003:187) identified principles and strategies for community-based programmes, especially for HIV/AIDS orphans, including amongst others, that:

- Siblings should remain together.
- Children should, as far as possible, remain in their homes or communities of origin.
- Caregivers should be supported through skills training in income-generation activities and child care skills.
- Development of communities is invariably a greater priority for communities, and programmes focusing on vulnerable children must ideally be linked to development programmes.
- Communities must provide support systems for both children and their caretakers.
- Criteria must be developed at community level for identifying their recipients of aid.
- Use must be made of locally recruited co-ordinators and volunteers who must receive appropriate training and supervision.
- Involvement in income-generating projects.
- Support should benefit the entire community.

- These responses must facilitate the provision of both direct and indirect material aid.

Uys and Cameron (2003:186) discussed some of the criteria that can be used to identify the children infected and affected by HIV/AIDS through community members as:

- Children living on their own with no adult supervision / guidance.
- Children living with a terminally ill parent.
- Children looked after by an elderly grandparent.
- Children not attending school.

In summary, community-based care as discussed in this chapter, through the involvement of different stakeholders offers a more conducive environment for children infected and affected by HIV/AIDS. In a community-based care setting these children are supported and cared for by families and community members who are there as support systems to address most of the challenges faced by these children. However, the challenge of any community-based model lies within the implementation phase. The Heartbeat community-based care model is one example, which will next be discussed.

2.5 THE HEARTBEAT'S COMMUNITY-BASED CARE MODEL

It was mentioned in Chapter 1 that the study used Heartbeat as a case study. Heartbeat is a non-governmental organisation that facilitates change in impoverished communities by alleviating the suffering of the poorest of the poor, with particular reference to children being orphaned mainly as a result of HIV/AIDS.

According to the Heartbeat brochure [SA], Heartbeat functions as a Centre for Community Development and renders services to HIV/AIDS orphans and children headed households within the community. It uses a community-based care model to take care of HIV/AIDS orphans in various communities in Gauteng, North West, Mpumalanga and Free State.

According to Venter (2004) Heartbeat's community-based care model is implemented through programmes based on children's rights and needs. It makes use of full-time employed staff members, caregivers and volunteers as community counsellors, in taking care of these children. The caregivers identify HIV/AIDS orphans with the help of the community and school teachers with the purpose to include them in the community-based care model.

Venter (2004) explained that the Heartbeat model focuses on the following aspects of community-based care:

- Mobilising communities for child care forums.
- Facilitating the establishment of day care centres, crèches and after-school centres.
- Offering care and support to children orphaned by HIV/AIDS.
- Issuing of food parcels and other material assistance.
- Capacity building, awareness programmes, training and development.
- Facilitating income-generating programmes.

Heartbeat is also involved in income-generating projects as discussed in the Heartbeat Newsletter (2003), which help in sustaining the programme over and above the funding that the organisation receives. These projects include:

- Beading.
- Sewing.
- Food gardening.

- Road rehabilitation.
- Candle-making.
- Pottery-making.
- Bakery.
- Memory box.

It should be noted however, that not all the provinces that Heartbeat collaborates with, are involved in all of these projects.

The Heartbeat brochure [SA] indicates that Heartbeat has established partnerships in communities comprising of churches, schools, clinics, local government, community-based organisations and the Department of Social Development. The components of the Heartbeat's community-based care model, as integrated with literature will next be discussed.

2.5.1 Creating a supportive environment through community participation

As discussed in this chapter, children orphaned by HIV/AIDS needs to be taken care of and supported in a familiar environment. Kay (2001:65) hinted that creating a supportive environment for all children involves initially developing a common attitude within the community environment, which is positive, child-centred and reflects clear views on respect for all, shared decision making and shared responsibility. This supportive environment involves mutual respect between adults and children, involving them in planning and trusting that they can make a valuable input in their own development.

McWhirter *et al.* (1998:215) stressed the importance of the relationship between vulnerable children and community members. According to these authors such a relationship provides a means by which young people learn academic skills and knowledge as well as necessary social skills. Adults can increase a sense of self-worth in children and adolescents. Children learn about effective and ineffective

social behaviour in their relationships with family members, school personnel, and other significant others.

The researcher ascertains that within the community-based care approach, organisations should make use of community members who have invested interest in the well-being of vulnerable children and the community. Heginbotham (1990:3) defines the concept voluntary as simply some activity or undertaking, offered in an open and generous spirit and given freely without any hint of coercion.

Uys and Cameron (2003:181) assert that volunteers from within the community are more likely to visit households regularly and that the help they offer is more likely to be practical and supportive. The role of outside organisations should thus be to assist communities through capacity building.

Lewis and Lewis (1989:108) propose that community members can identify groups or individuals at risk in their particular settings and can develop programmes that both provide support and strengthen problem-solving skills. They further stated that a number of community-based programmes have begun to demonstrate the tremendous potential of outreach programmes to vulnerable clients.

The community-based care model of Heartbeat provides for the establishment of after-school centres for HIV/AIDS orphans. The caregivers assist children with homework and life skills training. They also take the children on outings and field visits. Kay (2001:94) referred to outings as one of the most enjoyable activities for children. Children benefit from the break in routine. Trips and outings can be stimulating for children and caregivers alike, providing them with a change of pace and experiencing new thoughts, ideas and knowledge.

2.5.2. Meeting children's needs

Following from the discussion on children's rights by Kay (2001:15), Heartbeat's intervention is to ensure that orphans' rights are respected, through intervention strategies such as lobbying and education.

Heartbeat, as part of its programmes, creates awareness on the rights of children. HIV/AIDS orphans and the community at large are educated and empowered by Heartbeat on how to identify signs and symptoms of abuse. Heartbeat offers this kind of training to all staff members, caregivers, children and everyone who comes into contact with these children.

As previously indicated, the organisation also involves communities through community forums, established specifically to see to the welfare of HIV/AIDS orphans. Heartbeat identifies HIV/AIDS orphans who could be part of its programme through schools, community members and the local council. Uys and Cameron (2003:185) support the establishment of Community child care committees in all administrative areas to ensure that HIV/AIDS orphans, affected children, and their families are identified early and offered the necessary support.

King (1999) in Uys and Cameron (2003:189) present the recommendations of a study conducted in Swaziland regarding vulnerable children, one of which was that exemptions to homesteads/institutions with orphans and affected children. These include: enabling them to attend school; waiving school uniform requirements when affordability is a problem; expanding school-based feeding programmes for school children, and using national funds as an investment in the education of children.

Uys and Cameron (2003:177) emphasise that vulnerable children tend to be nutritionally deprived. Heartbeat provides for the basic needs of HIV/AIDS orphans. Through sponsorships and donations, the organisation is able to

provide food, clothing, and school materials such as uniforms, stationery and arrange for exempted school fees for these children. Heartbeat also provides support in helping children with homework, offer counselling and peer group activities such as outings, life skills training, and training in income-generating skills.

Heartbeat advocates for the rights and needs of children. One of the common concerns regarding vulnerable children is that they are susceptible to abuse. (Kay, 2001:103) alludes that there is a concern and a fear of confusing the normal everyday bumps and bruises a child receives with the symptoms of physical abuse. Kay (2001:103) further asserts that any report of child abuse should be treated confidentially and with respect. Sometimes children quite simply tell that they are being abused and when this happens, they should be listened to and a record of what the child said should be made as soon as possible.

2.5.3 Capacity building

Without life skills, children and adolescents are susceptible to high risk problem behaviours. Life skills are not just useful or handy; they are virtually essential. Uys and Cameron (2003:189) argue as follows about life skills training: “Every programme of care and support for HIV/AIDS orphans and affected children should include training to enable the children to cope more effectively with the situation in which they find themselves or to undertake the roles they are required to fulfil”.

McWhirter *et al.* (1993:270) reiterate that training in life skills for vulnerable children is the formal teaching of skills needed to succeed; to be able to live with others, and to survive in a complex society. These skills are not learnt automatically. Young people, especially those at risk, need help to acquire the social competence to cope with academic work, to make good decisions about

life's options, to adopt health promoting behaviours, to form stable human relationships, and to maintain hope about their future.

Heginbotham (1990:51) regards empowerment as part of community care which implies revaluing and empowering people to assist society to change in a way which will lessen any future tendency to devalue.

Uys and Cameron (2003:185) support the involvement of caregivers in capacity building, stating that they should be given further training in order to be effective in their diverse roles, including those related to identifying and supporting HIV/AIDS orphans and affected children.

Heartbeat's model aims to capacitate children infected and affected by HIV/AIDS with interpersonal and life skills. Whether community programmes operate at the level of the individual, institution, community, or the society at large, they are, in fact, empowerment strategies, designed to increase the degree of control people have over their lives (Lewis and Lewis, 1989:165).

McWhirter *et al.* (1993:223) explained that empowerment helps counsellors, teachers, young people and families to actively confront their environment rather than passively accept their conditions as unalterable. They define empowerment as the process by which people, organisations or groups that are powerless to:

- Become aware of the power dynamics at work in their life context.
- Develop the skills and capacity for gaining some reasonable control over their lives.
- Exercise this control without infringing upon the rights of others.
- Support the empowerment of others in their community.

McWhirter *et al.* (1993:225) indicate that from an empowerment perspective, professionals need to develop awareness of existing community organisations,

support groups, neighbourhood action committees, and other channels for collective effort. This perspective falls within the Heartbeat's model of community participation, as the organisation also make use of action committees and existing structures within the community. The community forum is an example of one such initiative.

By helping children and teens to assess the power dynamics in their lives, teaching them skills, not only for self-improvement but for the advancement of other, similar youngsters, and helping them to exercise new choices and behaviours allow them to recognise and use their own internal resources as human agents (McWhirter *et al.*, 1993:227).

As already discussed in 2.5.2, HIV/AIDS orphans and the community at large are educated and empowered by Heartbeat on how to identify signs and symptoms of abuse. Heartbeat offers this kind of training to all staff members, caregivers, children and everyone who comes into contact with these children.

2.5.4 Challenges for the Heartbeat's model

Heartbeat as an organisation has its limitations. Most of the HIV/AIDS orphans that they identify with the help of the community are homeless. There are no systems in place to ensure that HIV/AIDS orphans are granted title deeds, once they lose their parents. Consequently, most HIV/AIDS orphans are left homeless and some resort to criminal activities.

McWhirter *et al.* (1998:28) hinted that nowhere is the soil more fertile for at-risk problems than among those families that are homeless and that the potential at-risk problems of homeless children and adolescents are growing. However, the right to land is a challenge not only facing HIV/AIDS orphans, but the entire disadvantaged communities. The government is currently in the process of redressing the injustice and inequalities of the apartheid government, ten years

after the first democratic election in South Africa. The redistribution of land is slowly being addressed by the government and HIV/AIDS orphans are also caught up in this predicament, where they are left to fend for themselves, without a roof over their heads.

The researcher is of the opinion that different stakeholders such as government, in particular Departments of Land Affairs and Housing; private companies, NGOs and different community-based organisations should get involved in ensuring that HIV/AIDS orphans are entitled to land or shelter and other basic needs such as food and other material aid.

Heartbeat is not in a position to control community dynamics and the consistent support of the community in assisting children orphaned by HIV/AIDS. Part of the challenge faced by organisations such as Heartbeat is the lack of community members' involvement on a voluntary basis, especially in the South African context where volunteerism is still a major challenge, even after the South African president has declared 2004 the year of volunteerism.

The government should invest its resources in projects and programmes which are sustainable, in line with its strategy of eradicating poverty and taking care of HIV/AIDS orphans. Models such as the Heartbeat's community-based care model should continue to get full support from resourceful institutions and private companies through a government, public and private partnership.

2.6 Summary

In this chapter it was indicated that the HIV/AIDS pandemic has left many children orphaned to fend for themselves and cope with their grief and stress. There is a need for these children to be supported by their families within the context of community-based care, which was discussed as the best option for the care of children infected and affected by HIV/AIDS. The community plays an

important role in the identifying HIV/AIDS orphans in determining their needs and creating a support network amongst many stakeholders to integrate these children into society.

Heartbeat was discussed with reference to its community-based care model and the challenges the organisation face with regard to community-based care. Principles, criteria and strategies for community-based care were highlighted.

CHAPTER 3

EMPIRICAL STUDY AND RESEARCH FINDINGS

3.1 INTRODUCTION

In this chapter the research findings will be discussed based on the central themes extracted from the respondent's experience and perceptions. The researcher explored community-based care of HIV/AIDS orphans within the natural or field setting where the Heartbeat community-based care model is implemented in an attempt to make sense of the meanings that they bring to their personal experiences.

The researcher will briefly discuss the research methodology, provide a profile of the respondents, present the research findings according to different themes and where applicable, integrate literature with the findings.

3.2 RESEARCH METHODOLOGY

3.2.1 Research approach

The research followed a qualitative approach. Qualitative research produces descriptive data in the participant's own written or spoken words and involves the identification of the participant's beliefs and values that underlie the phenomena (Fouché & Delport, 2002:79). In line with a qualitative research approach, the goal of the research was to explore the components of community-based care of HIV/AIDS orphans in order to provide guidelines for a sustainable community-based model of care for these children.

3.2.2 Type of research

The researcher made use of applied research, which focuses on the usefulness of subjects and their behaviour. The goal of applied research is to provide a solution/s to a problem in practice (Smith, 1990:23). The study intended to determine the key components for community-based care of HIV/AIDS orphans. The focus was on determining these components which could then be utilised as guidelines for a community-based care model as a more sustainable alternative to institutions of care for children who are orphaned by HIV/AIDS.

3.2.3 Research design

The researcher conducted a case study, which is a qualitative research strategy. Durrheim and Lindegger (1999:255) states that a case study is an intensive investigation of particular individuals, single families, units, organisations, communities, or social policies. The qualitative researcher is therefore concerned with the understanding or rather the explanation and the subjective exploration of reality from the perspective of an insider (Fouché & Delport, 2002:79). The aim of a case study is to understand social life and the meaning that people attach to everyday life.

For this study Heartbeat, an NGO providing care and support for HIV/AIDS orphans, was used. Case studies are usually descriptive in nature and provide rich longitudinal information about individuals or particular situations (Lindegger, 1999:255).

3.2.4 Research population, sample and sampling method

Strydom and Venter (2002:198) explain that a universe refers to all potential subjects, who possess the attributes in which, the researcher is interested. A population, on the other hand, sets boundaries on the study units. It refers to

individuals in the universe, who possess specific characteristics. The research population consisted of caregivers, a volunteer and HIV/AIDS orphans based in Atteridgeville, a township outside of Pretoria, who are directly involved in implementing the model.

The sample for the HIV/AIDS orphans was drawn purposefully from the population of 116 HIV/AIDS orphans in Atteridgeville. Twenty of these orphans were purposively selected for the study according to the following criteria:

- Male and female.
- Aged between 12 and 18.
- Where one or both parents died.
- Child headed households with siblings.
- Supported by a caregiver or larger community (e.g. adopted for school fees or part of “Sponsor a child in need” project).

There are six caregivers in the Atteridgeville project and one volunteer who take care of the HIV/AIDS orphans, all of which were selected and interviewed for this study. No sample was therefore drawn for these two respondent groups.

3.2.5 Data collection method

Leedy (1993:139) points out that all data, all factual information, and all human knowledge must ultimately reach the researcher either as words or numbers.

Goddard and Melville (2001:49) indicate that an interview involves a one-on-one verbal interaction between the researcher and a respondent.

Greeff (2002:298) elaborates that a semi-structured interview is defined as being organised around areas of particular interest, while still allowing considerable flexibility in scope and depth. At the root of a semi-structured interview is an interest in understanding the experiences of other people and the meaning they

make of that experience. A semi-structured interview is also used to determine individuals' perceptions, opinions, facts and forecasts, and their reactions to initial findings and potential solutions (Greeff, 2002:298).

In this study a semi-structured interview schedule (see Annexure 1) was utilised to assist the researcher to understand the perceptions and experiences of Heartbeat caregivers, one volunteer and children orphaned by HIV/AIDS regarding key components of community-based care for HIV/AIDS orphans.

The data was collected by the researcher in the presence of a Heartbeat's professional community development facilitator. As indicated in Chapter 1, the Heartbeat's child protection policy (2004) states that a Heartbeat employee should be present when an outsider is in contact with the children. The researcher familiarised the community development facilitator with the interview schedule.

Greeff (2002:292) alludes, to one of the challenges facing researchers when they do qualitative research interviews as establishing rapport. The researcher was introduced to all the respondents and was given a chance to introduce himself. He explained the purpose of the research, indicated why the Atteridgeville project was chosen as the study unit, and explained how the interviews would be conducted and the importance of confidentiality and informed consent for participating in the study. Each participant was given a copy of the signed informed consent forms after the interviews.

3.3 DATA ANALYSIS PROCESS

De Vos (2002:339) explains that data analysis is the process of bringing order, structure and meaning to the mass of collected data. Qualitative data analysis is a search for general statements about relationships among categories of data; it builds grounded theory. Qualitative researchers collect data in the form of written

or spoken language, or in the form of observations that are recorded in language and then analyse the data by identifying and categorising themes (Durrheim & Lindegger, 1999:42).

Greeff (2002:318) indicates that the aim of analysis is to look for trends and patterns that reappear and that the basis for analysis is transcripts, tapes, notes and memory. The researcher, in this study made notes during the interviews.

The information gathered was organised according to a cross-sectional indexing system as suggested by Mason (1996:108). The researcher searched for general statements about relationships among categories of collected data and went through this information over and over again to make sense of the subjects' experiences and to become familiar with the data. The researcher wrote notes on the manuscript to help him explore the data further as outlined by De Vos (2002:343). He identified trends and patterns that reappeared in the responses as reflected in his notes and from his memory.

The themes that emerged from the data analysis will next be presented. De Vos (2002:344) calls this "packaging of what was found in text in tabular or figure form". As already indicated in the introduction, themes will be substantiated by direct quotes of respondents and verified by literature where applicable. At first, the profile of the respondents will be presented.

3.4 BIOGRAPHICAL DATA

The biographical data reflects the respondent group's gender, the age of HIV/AIDS orphans and the duration of the involvement of all the respondents in the Heartbeat programme.

3.1 GENDER

The gender of the respondent group (n=27) is indicated in Figure 3.1.

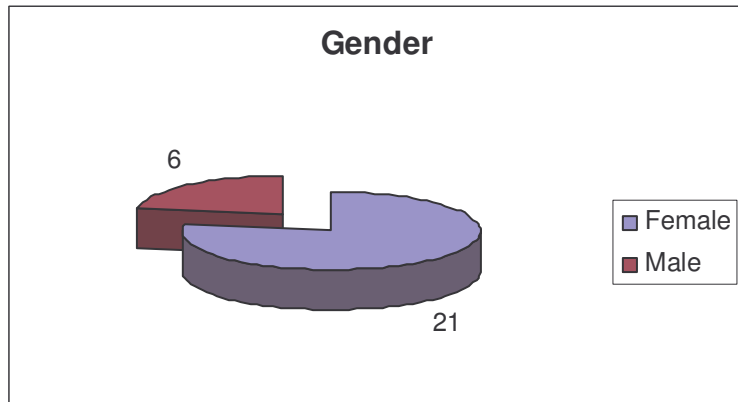


Figure 3.1 Gender of the respondent group

It is obvious from the above figure that most of the respondents in this programme are female. The seven caregivers and one volunteer only included women. The males reflected in Figure 3.1 therefore are from the orphan respondent group. However, this profile does not represent the gender profile of all the Heartbeat's staff members in the NGO.

3.2 ORPHAN'S AGE DISTRIBUTION

The age distribution of HIV/AIDS orphans is reflected in Figure 3.2.

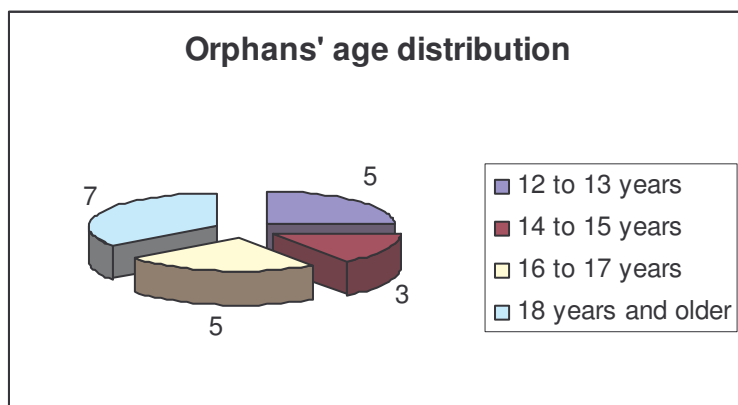


Figure 3.2 Orphans' age distribution

Although the majority of the respondents were 16 and older, Figure 3.2 indicates that children from all age groups are orphaned by HIV/AIDS. Uys and Cameron (2003:174) concurs that in 2001, UNAIDS released the facts that HIV/AIDS has orphaned at least 13 million children less than fifteen years of age.

3.3 DURATION IN THE PROGRAMME

The involvement of the respondent group (n=27) in the Heartbeat programme in Atteridgeville is reflected in Figure 3.3.

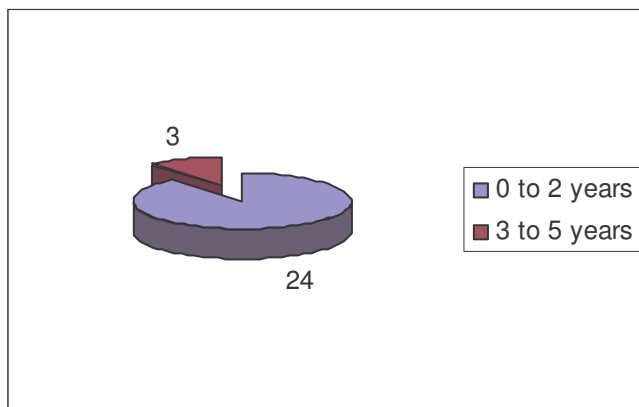


Figure 3.3 Respondents duration in the programme

It is evident from the figure above that most of the respondents have just joined the programme, with only three having been in the programme for longer than two years. Two of these respondents are HIV/AIDS orphans and one is a caregiver. This figure correlates with the duration of the programme itself which is due to the fact that the project in Atteridgeville is still in its infancy since it was only established in October 2002. The respondents however, were not less experienced in identifying the benefits of the programme for HIV/AIDS orphans.

3.5 RESEARCH FINDINGS

The research findings are integrated and will be presented as a collective for HIV/AIDS orphans, caregivers and the one volunteer. In order to voice the views

and perceptions of the respective respondent groups, direct quotes will be presented where applicable.

Themes that emerged from the research were as follows:

Theme 1: Relationship with caregivers

Theme 2: Heartbeat as a resource

Theme 3: The impact of the model

Theme 4: Community support and participation

Theme 4: Placement within the community

Theme 5: Challenges of the programme

Theme 1: Relationship with caregivers

In general the HIV/AIDS orphans regarded their relationship with caregivers as being good because they care for them, understand them and treat them as their children. The following quotes demonstrate the positive experiences of the relationship:

- “Good so far, they love, care for us, they listen, treat me well and understand us.”
- “Very good, enjoying our caregiver and spending time with her.”

Kay (2001:18) alludes to a number of different aspects of interaction between caregivers and children, which has an influence on their development. Some of the most important dimensions of interaction are as follows (Kay, 2001:18):

- Warmth (caring and expressing affection for the child).
- Responsiveness (tuning into the child’s needs, wants, moods and problems and responding to them).

The few respondents that indicated that the relationship was not satisfactory ascribed it to a caregiver being harsh. One view was expressed as follows:

“Not satisfied, sometimes they are harsh, but just one of them.”

Although one harsh caregiver can be one too many in the interest of a child, the findings indicated that the positive elements outweigh the negative elements of the relationship, as the following quote affirms:

“Sometimes it is good and sometimes its not, she helps the family and being over protective of us. I feel very happy when I am around Heartbeat staff members, because they make us feel free”.

Sharp and Cowie (1998:11) state that the early years lay a strong foundation for later emotional development and many of the difficulties experienced by children later on can be traced back to the first relationships with primary caregivers. The family plays an important role in the upbringing and socialisation of a child from an early age. In the absence of a family, caregivers play an important role to fill this gap.

Theme 2: Heartbeat as a resource

The respondents identified Heartbeat as a useful resource and indicated that the organisation assists them in meeting the basic needs of the children such as food, clothes, school uniform, fees and materials. The following quote provides a summary of the respondents' views:

“Makes life better for orphans. Most children were not at school. It takes them off the streets. Gives them food, blankets, clothes, school uniform, school materials, prevents teenage pregnancies, ill-treatments, drug abuse and raping of young girls. It gives them a sense of belonging, shelter and education.”

In addition, respondents indicated that their social needs were also met since Heartbeat facilitates, in the words of one respondent: “Going out socialising,

sports and entertainment”. Kay (2001:94) refers to the importance of outings as one of the most enjoyable activities for children. Children benefit from the break in routine. Kay continues in saying that trips and outings can be stimulating for children and caregivers alike, providing them with a change of space and experiencing new thoughts, ideas and knowledge.

Respondents indicated that Heartbeat protects the children’s rights. One respondent voiced this protection as follows: “Children’s rights and well-being of orphans are protected”.

This finding confirmed what Venter, the programme manager of Heartbeat said during an interview (17 March, 2004), namely that Heartbeat’s community-based care model provides the context for programme implementation based on children’s rights and needs. The programme offers care and support to children orphaned by HIV/AIDS and issues food parcels and other material assistance to these children.

Theme 3: The impact of the model

The respondents acknowledged that the model has made a significant impact on the lives of HIV/AIDS orphans and shared the following view:

“The model is helping the children who are orphaned by HIV/AIDS, it has made a difference in their lives and children can voice their feelings.”

With regard to their position in society, a few orphan respondents indicated that they were able to identify with other children at school and stated that they see themselves similar to them. However, many of the orphan respondents perceived themselves different from other children who are not in the programme by saying:

“It’s not the same, sometimes I need stuff that I can’t get, which other children have and when they call parents you feel lonely for not having one.”

One respondent had mixed feelings about the impact of the programme relating to other children at school:

“It’s the same, but you get shy because of the stigma of being in the programme.”

Venter (2004) argued that it is inevitable that the programme has an impact on the lives of these children as it facilitates the establishment of day care centres, crèches and after-school centres and provides care and support to children orphaned by HIV/AIDS.

Theme 4: Community support and participation

The respondents had different views on the extent of community participation and support that the community offers to HIV/AIDS orphans. Most respondents reported positive experiences with regard to community support and participation as reflected in the following quotes:

- “They teach us respect, guidance and caring for each other, visiting us at night and protecting us. They are very supportive, helpful and advising.”
- “They help with food, utensils, clothes, uniform, buying electricity, soap and pocket money.”
- “They identify orphans and problems within the community.”
- “They help when there are deaths in the family with funeral arrangements.”

Uys and Cameron (2003:181) assert that volunteers from within the community are more likely to visit households regularly and the help they offer is more likely to be practical and supportive.

Lewis and Lewis (1989:108) concur that community members could identify vulnerable groups or individuals in their particular settings and develop programmes that provide both support and strengthen problem-solving skills. They further allude that a number of community-based programmes have begun

to demonstrate the tremendous potential of outreach programmes to vulnerable clients.

Members of the community are in the best position to know which households are most severely affected and what sort of help is appropriate. They know who is dying, who has died, who has been taken in by relatives, who is living alone, and who has enough to eat (Uys and Cameron, 2003:181).

However, a few of the respondents were not appreciative of the community's involvement as the following quote reflects:

“They are not that helpful; they are very ignorant and do not care about somebody else's child.”

One respondent stated that the community only helps if they expect something in return: “They only give when we ask and there is a price to pay.”

McWhirter *et al.* (1998:215) stressed the importance of the relationship between vulnerable children and community members. They emphasise that such a relationship provides a means by which young people learn academic skills and knowledge as well as necessary social skills.

Uys and Cameron (2003:181) add that there is general consensus that interventions to assist HIV/AIDS orphans and affected children should be based in, and owned by, the affected communities themselves. More involvement by community members should therefore be encouraged.

Theme 5: Placement within the community

There were an overwhelming number of respondents who cited that HIV/AIDS orphans should be placed within the community, thus in a familiar environment.

The importance of such placement is summarised in the following quotes:

- “In the community, community members guide you and you mix with others. You get support from people and seeing your friends and freedom, you don’t feel isolated and avoid stigmatization. Within the community, we can play and visit friends, but staying in a place of safety is like living in hell and separating us from our friends.”
- “In the community where they will have a sense of belonging, love, care in the comfort of their homes.”

Thoburn (1994:37) supports the permanent placement for children in a familiar environment and regard it as crucial for their development.

However, there was a view by two caregivers and one HIV/AIDS orphan that infants should be placed in a place of safety as reflected in the following quotes:

- “Children should be left within the community, but those between the ages of zero to three years should be placed in a place of safety.”
- “They should be placed in places of safety, where they will be looked after full-time with guaranteed meals and safety, giving caregivers a chance to go home after work.”
- “I really love the place of safety, because I will meet new friends like myself.”

The respondents’ views on how children orphaned by HIV/AIDS should be taken care of in both the community and place of safety are summarised as follows:

“They must get support from their families and relatives and not be ill-treated. They must be given food, shelter, education and a safe environment.”

Uys and Cameron (2003:182) stated that family and community-based approaches appear to best meet the child’s need for security and socialisation; however, they need to be supported and strengthened if they are to remain a viable way of meeting all the needs of the child.

Theme 6: Challenges of the Heartbeat model

The respondents acknowledged that the Heartbeat model is very helpful, but that it has some challenges as one respondent commented: “The model is working, but there are some challenges”.

The respondents’ opinions were that if these challenges could be addressed, it would even make a larger impact or difference in the lives of HIV/AIDS orphans. Respondents indicated the following challenges:

- “The criteria of selecting families should be reviewed to accommodate more children.”
- “Provide more shelter, medication and treatment for orphans.”
- “Improve the quality of food. Children are only getting non-perishables (canned food). There is no variety like meat and vegetables. Remuneration is unsatisfactory.”
- “Extend the community centre to accommodate more children for after care activities, because the number of children is too many.”
- “The model should also assist vulnerable children, family members and relatives who are unemployed.”
- “The model could help more when a child is deceased. Remuneration can be looked at since the caregivers are not benefiting from the funds like provision of clothes for their own children.”

During an interview with Venter (17 March, 2004), she acknowledged that Heartbeat as an organisation has its limitations. Venter (2004) reiterated that most of the orphans are homeless and that there are no systems in place to ensure that orphans are granted title deeds, once they lose their parents. Venter (2004) emphasised that Heartbeat is also not in a position to control community dynamics and to ensure the consistent support of the community in assisting children orphaned by HIV/AIDS.

It is encouraging for partnerships to note that both the management of the Heartbeat organisation (compare Chapter 2, sub-section 2.5.4) and the respondents identified gaps and challenges in the community-based care model in Atteridgeville.

3.6 SUMMARY

In this chapter the researcher discussed the research methodology that informed the research study and indicated how the data was analysed. The profiles of the respondents were indicated and the findings of the study were presented according to themes that emerged from the data, where applicable findings were verified by literature.

Chapter 4 will focus on the key findings, the conclusions and recommendations of the study.

CHAPTER 4

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

In this chapter the researcher will indicate how the objectives of the study were achieved and by doing so summarise the findings of both the literature and the empirical study with the purpose of highlighting the key findings of the study. The conclusions will be drawn from these key findings, which in turn will inform the recommendations of the study.

4.2 GOAL AND OBJECTIVES OF THE STUDY

The goal of the study was to explore community-based care of HIV/AIDS orphans in order to provide guidelines for a sustainable community-based model of care for these children.

The objectives of this study were achieved through a literature and empirical study as will subsequently be indicated under the respective objectives.

Objective 1

To conceptualise community-based care for the care of HIV/AIDS orphans.

This objective was met through both the literature and empirical study.

In this study community-based care was found to be a viable option for the care and support of HIV/AIDS orphans, as opposed to institutionalisation of these children (compare Chapter 2, sub-section 2.5.1). Findings indicated that community participation, care and support play a significant role in the placement of HIV/AIDS orphans within the community which is a familiar environment for them (compare Chapter 3, section 3.4).

Paul (1987) in Mayo and Craig (1995:2) defined community participation as a means for ensuring that Third World development projects reach the poorest in the most efficient and cost-effective way, and sharing costs as well as benefits, through the promotion of self-help. In this study findings indicated that *community participation* refers to the voluntary involvement of community members in the care and support of children orphaned by HIV/AIDS (compare Chapter 1, sub-section 1.11.3).

Findings further indicated that community-based care through the involvement of the community, offers a more conducive environment for children orphaned by HIV/AIDS (compare Chapter 3, section 3.1). The community was identified as a significant partner in the Heartbeat community-based care model for community participation, however, not without challenges (compare Chapter 2, sub-section 2.5.4). Families and community members such as caregivers are significant care and support systems to address most of the challenges faced by these children (compare Chapter 2, sub-section 2.3.3).

Findings proposed that the community could assist in providing the basic day-to-day needs of HIV/AIDS orphans as well as emotional support. The community could also support both the children and their caregivers as well as act as a forum for lobbying authorities to assist in providing an effective response to the needs of these children (compare Chapter 2 sub-section 2.4.2). McWhirter *et al.* (1998:215) stressed the importance of the relationship between vulnerable children and community members.

As discussed in Chapter 2 (sub-section 2.3.3), Uys and Cameron (2003:181) concur that there is general consensus that interventions to assist orphans and affected children should be based in, and owned by, the affected communities themselves. These authors identified principles and strategies for community-based programmes, especially for HIV/AIDS orphans and suggested how community participation could be encouraged namely:

- Communities must provide support systems for both children and their caretakers.
- Locally recruited co-ordinators and volunteers, who receive appropriate training and supervision, must be utilised as resources.
- The community should be involved in income-generating projects.
- Support should benefit the entire community (Uys and Cameron, 2003:187).

Findings from the Heartbeat model indicated that a community-based care model should reflect a comprehensive developmental approach, which encourages community participation, income generation projects, sustainable development and the creation of an enabling environment for community participation and involvement (compare Chapter 2, section 2.5).

Objective 2

To determine the directions and limitations with regard to community-based care within the current policy framework for caring for children infected and affected by HIV/AIDS.

This objective was met through the literature study (compare Chapter 2, subsection 2.3.1).

Policies were adopted in South Africa such as the Reconstruction and Development Programme (1994), the White Paper for Social Welfare (1997) and the Financing Policy for Developmental Social Services (1999) to guide service delivery to vulnerable groups, including children infected and affected by HIV/AIDS. The National Guidelines on Home Base and Community Based Care (2000c) and the National Guidelines for Social Services to Children Infected and Affected by HIV/AIDS (2002b) flowed from the White Paper for Social Welfare (1997). The purpose of these guidelines is to address issues around the welfare

of children infected and affected by HIV/AIDS and to enhance and facilitate community based care.

The government, in its national guidelines for social services to children infected and affected by HIV/AIDS, stated that the home/community-based care and support strategy developed by the Department of Social Development, is based on the premises that children are better protected when cared for in the context of their communities (Department of Social Development, 2002b). This approach is in line with the aim of the social welfare policy, namely to build a self-reliant community, which is equitable, sustainable, accessible, people-centred and developmental (White Paper for Social welfare, 1997). The developmental approach for social welfare provides a theoretical framework for a community-based approach to HIV/AIDS orphans (compare Chapter 2, section 2.3).

It was pointed out in Chapter 2 (section 2.1) that although there are organisations that have developed and implemented a community-based care model based on the above guidelines, there is a concern about the lack of government's intervention in monitoring the implementation of these guidelines by such organisations. This poses a challenge to government to collaborate and cooperate with Non-Governmental Organisations, Community-Based Organisations, Health and other professionals and volunteers to fully participate in the care and support of HIV/AIDS orphans.

Objective 3

To identify the components of Heartbeat's model for community participation for community-based care of HIV/AIDS orphans.

This objective was met through the interview with Venter (2004), Heartbeat documentation and the empirical findings. Research findings indicated the components of Heartbeat's community-based care model for HIV/AIDS orphans as follows:

- Placements of children are done within the community in an environment more familiar to them under the supervision of a caregiver, family member, relative or an older child in cases where the HIV/AIDS orphans do not have family members (compare Chapter 3, section 3.4). Thoburn (1994:73) argues that there is no doubt that a youngster's need for stability and security, together with his or her need for a sense of personal identity, can best be met by returning permanently to live with both or at least one natural parent, provided that they can provide "good enough" care, either alone, or with continued help (compare Chapter 2, sub-section 2.4.2).

The Heartbeat model emphasises a good relationship between caregivers and HIV/AIDS orphans (compare Chapter 3, section 3.4). This finding was supported by literature since these children are more comfortable and attached to their immediate family or their community (compare Chapter 2, sub-sections 2.4.2 and 2.5.1).

- Heartbeat serves as a resource that facilitates the establishment of community facilities such as after-school centre, day care centres and crèches (compare Chapter 2, section 2.5 and sub-section 2.5.1 and Chapter 3, section 3.4).
- Heartbeat lobbies and protects children's rights and needs through advocacy and the issuing of food parcels and other material assistance, including clothes and school fees (compare Chapter 3, section 3.4).
- Heartbeat capacitates, trains and equips caregivers and everyone who becomes involved with HIV/AIDS orphans, including community members (compare Chapter 3, section 3.4).

Objective 4

To determine the key components for effective community-based care for the care of HIV/AIDS orphans, which could serve as guidelines for a sustainable community-based care model for these children.

This objective was met through the literature study (compare Chapter 2, sub-sections 2.3.3 and 2.4.2.1) and the empirical study (compare Chapter 3, section 3.4). These findings informed the guidelines for a community-based care model for the care of HIV/AIDS orphans which are presented under conclusions.

The proposed guidelines answered the research question of the study, namely:

What are the key components of a community-based care model for the care of HIV/AIDS orphans?

4.3 CONCLUSIONS

Based on the key findings of the study, the following conclusions were made:

- There is a lack of policies to guide, support, and monitor the establishment of community-based care of children orphaned by HIV/AIDS. The Department of Social Development should develop policies to monitor existing organisations implementing a community-based care model for HIV/AIDS orphans in order to create an enabling environment for community participation and involvement.
- Community-based care models should be established in line with the developmental approach to facilitate human and social development and income-generating projects for sustainable development.

- Community participation is crucial in the placement, support and care of HIV/AIDS orphans within their communities. This participation should include stakeholders such as churches, schools, NGOs, the private sector and community organisations.
- Partnerships for community-based care should be established amongst community-based organisations, non-governmental organisations, civic organisations, schools, churches and community members. These role players should get involved in the identification and placement of HIV/AIDS orphans, they should plan and assist in meeting the HIV/AIDS orphans' basic needs, offer protection, guidance, assist if there are deaths and be part of community forums to advocate and lobby on behalf of HIV/AIDS orphans.

Guidelines for a sustainable community-based care model for HIV/AIDS orphans should include the following components as principles for community placement:

- Children orphaned by HIV/AIDS should be placed and care for within their own community which is familiar to them. Siblings should be placed together as far as possible. Children in care of themselves such as child-headed households should be under the supervision of caregivers.
- The government, community and all key actors should protect the rights and needs of HIV/AIDS orphans. There should be provision of shelter and allocation of title deeds for HIV/AIDS orphans in their communities. Facilities such as day care centres, crèches and after-school centres should be available for HIV/AIDS orphans either by integrating them in existing ones or establishing new ones if the need exists.

- There should be clear guidelines for identifying HIV/AIDS orphans in communities with the help of community members and different structures within the community.
- The community should provide for support systems for children orphaned by HIV/AIDS and should provide these children with material assistance in meeting their basic needs such as food and clothes.
- Volunteers or caregivers monitoring HIV/AIDS orphans should come from the community and must be capacitated on how to care for and support these children, to teach them life skills to enable them to deal with life's challenges.
- Key actors in the community should include the church, school, CBOs, NGOs, civic organisations, the private sector and local council and intermediary organisations such as Heartbeat should be involved in lobbying support and advocating for HIV/AIDS orphans' rights and needs with the relevant key actors.
- There should be exemption of school fees and provision of school materials for HIV/AIDS orphans. The Department of Education should be approached to exempt HIV/AIDS orphans from paying school fees and assist the children in the acquisition of school materials and uniforms. The Department of Housing should be approached to provide shelter or title deeds to HIV/AIDS orphans, who have no place to stay, within the community.
- Organisations dealing with HIV/AIDS orphans should only get funding if they can provide a project plan which clearly indicates

sustainable goals, in line with the developmental approach and complies with government legislation.

- Government should provide clear guidelines for monitoring and evaluating of organisations involved in community-based care for HIV/AIDS orphans to ensure compliance.

4.4 RECOMMENDATIONS

The recommendations from the study are as follows:

- Existing policies and guidelines addressing children infected and affected by HIV/AIDS should be revised in view of the proposed guidelines for a sustainable community-based care model for HIV/AIDS orphans.
- Monitoring and evaluation mechanism for community-based care of HIV/AIDS orphans should be designed and implemented by the Department of Social Development to protect these children's rights and address their needs.
- Government should pledge material resources for HIV/AIDS orphans with regard to:
 - Exemption of school fees;
 - Access to land, housing, electricity and water;
 - Financial support of NGOs and CBOs engaged in community-based care; and
 - Skills training in income-generating projects of caregivers and HIV/AIDS orphans to ensure sustainable livelihoods.

- Research should be done on the impact of community-based care programmes on the well-being and quality of life of HIV/AIDS orphans, caregivers, families and the larger community in terms of sustainable livelihoods.

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ANNEXURE 1

BIOGRAPHICAL INFORMATION

HEARTBEAT STAFF MEMBERS AND CAREGIVERS

Gender:	Male <input type="checkbox"/> Female <input type="checkbox"/>
Occupation:	Staff member <input type="checkbox"/> Caregiver <input type="checkbox"/> Other <input type="checkbox"/>
How long have you been with Heartbeat:	0 – 2 years <input type="checkbox"/> 3 – 5 years <input type="checkbox"/> 6 – 8 years <input type="checkbox"/> 9 + years <input type="checkbox"/>

1. What does the Heartbeat’s community-based model entail?
2. What is in your view, the impact of the model on the orphans and the community?
3. What difference is the model making in the lives of orphans and the community?
4. Explain the different responsibilities and partnerships amongst the role players / stakeholders.
5. How involved are these role players in the care and support of orphans?
6. Which areas of the model work very well and which ones need improvement.
7. What is your view on placing orphans in a place of safety as opposed to leaving them in the community?

BIOGRAPHICAL INFORMATION

ORPHANS

Gender:	Male <input type="checkbox"/> Female <input type="checkbox"/>
Age:	12 – 13 <input type="checkbox"/> 14 – 15 <input type="checkbox"/> 16 – 17 <input type="checkbox"/> 18 + <input type="checkbox"/>
Grade:	1 – 4 <input type="checkbox"/> 5 – 8 <input type="checkbox"/> 9 – 12 <input type="checkbox"/> Other <input type="checkbox"/>
How long have you been with Heartbeat:	0 – 2 years <input type="checkbox"/> 3 – 5 years <input type="checkbox"/> 6 – 8 years <input type="checkbox"/> 9 + years <input type="checkbox"/>

1. How long have you been involved with Heartbeat?
2. How would you describe your relationship with the caregivers and Heartbeat staff members?
3. How is Heartbeat helping you?
4. How do you compare your life with other children?
5. How helpful are people in the community?
6. In your own view, how should children without parents be taken care of?
7. What do you think about placing children in places of care as opposed to leaving them in the community?

ANNEXURE 2

INFORMED CONSENT FORM FOR RESPONDENTS

Researcher: Tshifhiwa Mamaila
PO Box 23087
Joubert Park
2044

1. Title of Study: Community –based care for HIV/AIDS orphans.

Purpose of the Study: The purpose of this research study is to explore and gain insight into community-based care of HIV/AIDS orphans in order to provide guidelines for a sustainable community-based model of care for these children

Participant's Name: **Date:**

Procedures: I understand that I will be invited to engage in an interview at my convenience with the researcher to explore community-based care for HIV/AIDS orphans. I understand that I will be asked questions relevant to the purpose of the study.

2. Risks and Discomforts: I take note that there are no known medical risks or discomforts associated with this research.

3. Benefits: I understand there are no known direct benefits to me for participating in this study. However, the results of the study may help the government and other organizations in the caring of HIV/AIDS orphans.

4. Participant's Rights: I understand that I may withdraw from participating in the study at any time.

5. Financial Compensation: I understand that I will not be reimbursed for my participation in the study.

Confidentiality: I understand that the researcher will take all reasonable steps to protect the confidentiality of research respondents and that he will refrain from identifying me in his research report or any other publications related to this research.

By signing the consent form, I confirm that I have read this informed consent form and that the study has been explained to me and that I give consent to voluntarily participate in this study. I understand my rights as a researcher subject and that I do not give up any legal right by signing this informed consent form. I take note that I will receive a signed copy of this consent form.

Subject's Signature

DATE

Signature of Researcher

I will fly like an eagle

I could only count the months,
As far back as I would like my memory to remember.
I could not recognise my father's voice,
My mother's face I remember seeing,
Though I would not have been able to remember it,
If it was not for the photo that I keep always.

I hear she passed on months after my father left,
They were both very ill.
I always thought that I might have taken my mother's life,
She did not live long after I was born.
I guess I will never know the sweet sound of her voice,
Nor the mother's love to her child.

I was told that she is watching over me,
I sometimes look towards the sky if I need her help.
I am not sure if she does hear me,
But she keeps coming to my dreams,
And wake up looking forward to our reunion.
Only to find that it was a dream.

I wish I could bring her back,
(Chuckle) So she could see how big I have grown.
I wish I had the wings to fly like an eagle.
Maybe I will be able to reach her,
If I could fly beyond the sky.
It would be worth the trip every now and then.
That's why I want to be an astronaut.

By: Tshifhiwa Mamaila



HEARTBEAT

Centre for Community Development

Tel: 012 803 3970, Fax: 012 803 9712, Email: heartbeat@web.co.za

13 May 2004


To Whom It May Concern:

Dear sir/ madam

Heartbeat's management hereby gives permission that Tshifwa Mamaila do his research as part of the fulfilment of his MSD (Social Development and Policy) studies at one of the communities that Heartbeat currently intervenes with.

For any other information you can contact the Regional Programme Manager, Ms. Maryke Venter at 012 803 3970.

Kind regards,


Dr. Sinette Pienaar
Heartbeat: General Manager



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