

**GUIDELINES FOR SOCIAL WORK INTERVENTIONS WITH  
CHILDREN AFFECTED BY HIV AND AIDS**



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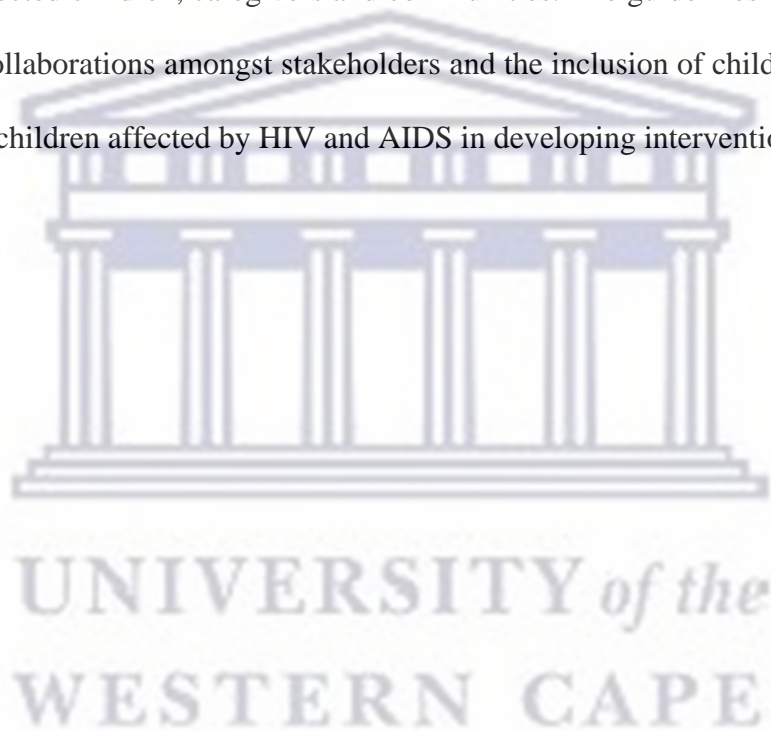
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## **ABSTRACT**

Children affected by HIV and AIDS are often left without adult supervision when the parent or caregiver ultimately dies from HIV and AIDS-related illnesses, leaving them vulnerable to exploitation and in need of care. Children in need of care are required by law to be attended to by social workers who need to make sure that they design interventions that will be able to protect the rights of children. Various stakeholders across Africa have implemented a number of interventions in an attempt to support children affected by HIV. Still, these interventions do not clearly define the social worker's role. This study aimed to develop guidelines for social work interventions with children affected by HIV and AIDS. The study used an intervention mapping research design implemented over two phases using the Ecological Systems Theory. The first phase focused on a needs assessment which was done through three stages focusing on: a systematic review to explore best practice interventions used with children affected by HIV for community-based care and support, interviews with various organisations to identify and describe the intervention models used by the organisations working with children affected by HIV and AIDS; interviews with social workers to explore their experiences of using interventions with children affected by HIV and AIDS. The second phase focused on developing guidelines and was implemented in two stages. The first stage focused on conducting a Delphi workshop with a panel of experts in health, child and youth care, family interventions, community work and research. The second stage was a workshop with stakeholders working with children and families affected by HIV and AIDS who were professionals from the disciplines of social work, psychology, physiotherapy and academics. This study resulted in the development of guidelines for social workers working with children affected by HIV and AIDS as a process to be followed by practitioners when implementing



interventions for children affected by HIV and AIDS. The guidelines involve identification of the needs through screening and assessment; psychosocial support for HIV-affected children and their families; information dissemination; community-based outreach programs; education support for CABHA; parenting support for caregivers that embraces diversity and encourages social inclusion; organizational development focused on regular training, supervision and capacity building of staff. The guidelines are meant to strengthen existing social work intervention methods and provide guidance to organisations to ensure that their interventions support HIV-affected children, caregivers and communities. The guidelines also highlight the importance of collaborations amongst stakeholders and the inclusion of children, families and communities of children affected by HIV and AIDS in developing interventions.



## KEYWORDS

HIV

AIDS

Children

Caregiver

Community

Family

Family systems theory

Interventions

Intervention mapping

Parents

Social worker



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## DEFINITION OF TERMS

**HIV:** Human immunodeficiency virus (HIV) is an infection that attacks the body's immune system, specifically the white blood cells called CD4 cells. (WHO, World Health Organization, 2022)

**AIDS:** Acquired immunodeficiency syndrome (AIDS) is a term that applies to the most advanced stages of HIV infection. It is defined by the occurrence of any of the more than 20 life-threatening cancers or "opportunistic infections", so named because they take advantage of a weakened immune system. (WHO, WHO news-room questions and answers, 2020)

**Children affected by HIV and AIDS:** Children living with HIV, as well as those whose well-being or development is threatened by HIV because they live in HIV-affected households and communities" (UNICEF, Taking Evidence to Impact: making a difference for vulnerable children living in a world with HIV/AIDS, 2011)

**Caregiver:** Any person other than a parent or guardian who factually cares for a child and includes- a foster parent; a person who cares for a child with the implied or express consent of a parent or guardian of the child; a person who cares for a child whilst the child is in temporary safe care; the person at the head of a child and youth care centre where a child has been placed; the person at the head of a shelter; a child and youth care worker who cares for a child who is without appropriate family care in the community (Republic of South Africa, 2005)

**Family:** A societal group that is related by blood (kinship), adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation and go beyond a particular physical residence (White Paper on Families, 2021)

**Family strengthening:** The deliberate process of giving families access to the necessary opportunities, relationships, networks, and support to become functional and self-reliant. The strengthening of families is driven by certain core areas: economic success, family support systems, and thriving and nurturing communities. (White Paper on Families, 2021)

**Family support:** Services targeted to families in particular types of situations, which include families considered at risk of social exclusion or in marginalised sectors of the population; those where the children have special needs (such as a disability of some kind); those where the children are considered to be subject to some risk (such as violence, child neglect or abandonment); or where children need kinship care due to orphanhood or HIV/AIDS (Daly et al., 2015)

**Guidelines:** Documents that synthesise current evidence on how to most effectively organise and deliver health services for a given condition (Gagliardi, Marshall, Huckson, James, & Moore, 2015)

**Orphan:** A child with no surviving parent caring for him or her.

**Vulnerable child:** A child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance and which prevents the fulfilment of his or her rights.

## DECLARATION

I hereby declare that this dissertation, **GUIDELINES FOR SOCIAL WORK INTERVENTIONS WITH CHILDREN AFFECTED BY HIV AND AIDS**, is my work and that all resources that were used or referred to by me during the research study are completely acknowledged through a complete reference or an acknowledgement statement.

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## DEDICATION

I dedicate this thesis to my late sister, Zandile Lukelelo, who was there cheering me on when I began this journey but passed away before I could complete it. May her beautiful soul continue to rest in peace. You may be gone but your spirit lives in my heart, maGaba.



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## **ABBREVIATIONS AND ACRONYMS**

**AIDS** - Acquired Immunodeficiency Syndrome

**CABHA** - Children Affected by HIV and AIDS

**COVID 19** - Corona Virus Disease of 2019

**CSF** - Civil Society Forum

**DOH** - Department of Health

**EST** – Ecological Systems Theory

**HIV** - Human immunodeficiency virus

**IM** - Intervention Mapping

**NGOS** - Non-Governmental Organisations

**NSP** - National Strategic Plan

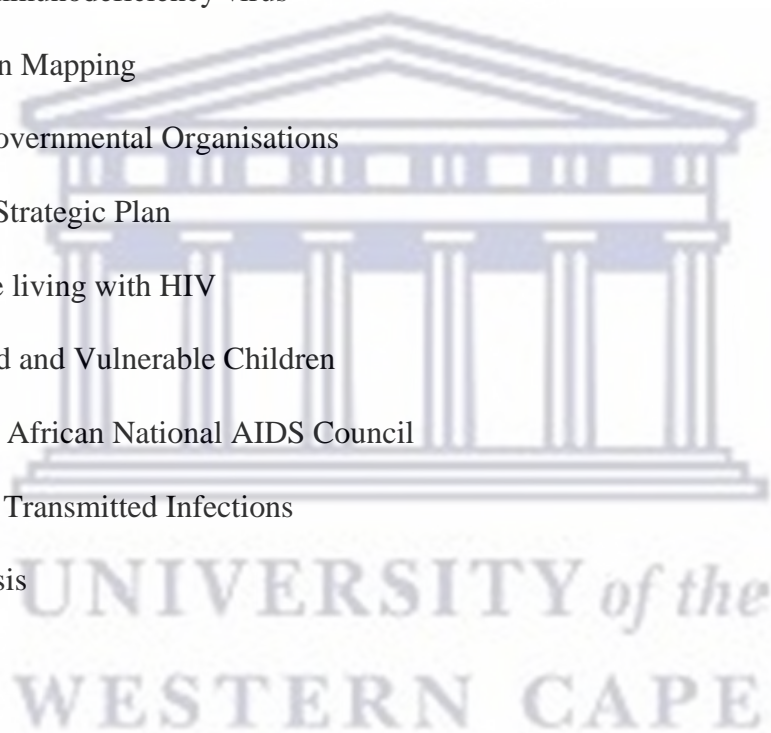
**PLWH** – People living with HIV

**OVC** - Orphaned and Vulnerable Children

**SANAC** - South African National AIDS Council

**STIs** – Sexually Transmitted Infections

**TB** – Tuberculosis



# CHAPTER 1

## INTRODUCTION

### 1.1 INTRODUCTION

This chapter is an introduction that provides an overview of the study. The first section gives background information on the prevalence of HIV and AIDS in the global, African and South African context. Further discussion in the chapter focuses on the impact that HIV has on the child, family and communities and the role of social workers in meeting the needs of children affected by HIV and AIDS. The problem statement, research question, aims and objectives are also explained. Followed by a discussion of the research methodology, significance of the study and ethical considerations. The chapter concludes by giving an outline of the thesis.

### 1.2 BACKGROUND OF THE STUDY

Social workers are required to deal with many of the consequences of social inequality, poverty and marginalisation, which include, amongst other things, HIV and AIDS. AIDS remains one of the world's biggest health challenges affecting many people. Since the beginning of the epidemic, UNAIDS (2022) reports that the number of people living with HIV (PLWH) is estimated to be approximately 38 million, and about 40.1 million people have died of AIDS-related illnesses. This indicates that the number of people living with HIV continues to grow compared to a decade ago, which was reported by UNAIDS (2012) to be around 34 million. In South Africa, the number of people living with HIV has increased from 3,68 million in 2002 to 8,5 million in 2022 (Stats SA, 2022). This increase in the number of people living with HIV has increased due to access to anti-retroviral therapy, as people with HIV live longer than they normally would have if they did not have ART available to them. The implications of receiving

ART are that AIDS-related deaths still occur but potentially decrease. The diagnosis of HIV still raises concerns in most people about the possibility of death from HIV and AIDS-related illnesses. Stats SA (2022) reports that AIDS-related deaths have remained prevalent in South Africa for over two decades.

UNICEF (2022) estimates that 14.9 million children worldwide have lost one or both parents due to an AIDS-related cause in 2021, and three-quarters of these children live in sub-Saharan Africa. Furthermore, it is also estimated that over a fourth of South African women in their reproductive ages are HIV positive (StatsSA, Mid-year population estimates, 2022), which means that these women will ultimately die from HIV and AIDS-related illnesses, thus leaving their children behind. Furthermore, the increasing number of HIV-related deaths results in children being left behind with limited to no source of support. One of the most tragic consequences of the HIV and AIDS epidemic is the number of orphaned children due to parents dying from AIDS (Bradshaw, Johnson, Schneider, Bourne, & Dorrington, 2002). These children are often called Orphaned and Vulnerable Children (OVC), which sometimes includes children affected by HIV and AIDS (CABHA). This puts strain on extended families and pressure on government and community resources. Family structures and roles also change due to the AIDS epidemic. Children end up being cared for by extended family members when their parents cannot care for them because of deteriorating health or death due to HIV and AIDS-related illnesses (Breckenridge et al., 2019; Goldberg & Short, 2016; Linsk & Mason, 2004). Families and communities carry most of the burden of HIV's impact on children and therefore require support from relevant stakeholders to ease the load. This indicates a need for intervention by various stakeholders involved in the care and support of children affected by HIV.

In 2019 the world was faced with a new pandemic, COVID-19, which threatened the health and lives of everyone. Previous studies have reported the HIV and AIDS pandemic's significant social and economic impact on family households (Breckenridge et al., 2019; Sherr, et al., 2014; Ssewamala et al., 2016), and the emergence of COVID in 2019 only exacerbated this. The UNAIDS (2022) reports that the colliding AIDS and COVID-19 pandemics and economic and humanitarian crises have placed the global HIV response under increasing threat. This means that the HIV and AIDS epidemic is more than just a health problem but also affects the general well-being of families.

Various intervention models have been implemented across Africa (Betancourt et al., 2014; Bhana et al., 2010; Ssewamala et al., 2016), containing different interventions for children affected by HIV and AIDS in African countries. Bhana et al. (2010) implemented a Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP), which is a family-focused, developmentally timed programme for pre-and early adolescents, by providing a model of primary and secondary HIV prevention programme development. Similarly, Betancourt et al. (2014) implemented a Family Strengthening Intervention (FSI) to reduce mental health problems among HIV-affected children through improved child-caregiver relationships, family communication and parenting skills. Ssewamala et al. (2016) applied a family-level economic strengthening intervention to improve education and health-related outcomes of school-going AIDS orphaned children. The interventions used different approaches, which are mostly family-based and attend to the different needs of the families of CABHA. Although these interventions were aimed at CABHA, they were specifically aimed at different target groups such as children, grandparents and others involved in caring for CABHA to provide psychosocial and economic support to children affected by HIV and AIDS.

None of these interventions mentions the role of social workers. No evidence was reported on these interventions to show their effectiveness or whether they would apply to different contexts.

The National government of South Africa adopted a National Strategic Plan (NSP) for 2017 to 2022, which provides a framework from which different stakeholders involved in HIV, TB and STI work can work and develop intervention programs. It is aimed at addressing social and structural factors that drive epidemics (including HIV), influence their impact and affect the way government cares for HIV-infected and affected people. This strategic plan is very broad and is not specific to the social work profession or gives guidelines on how interventions for CABHA should be. This indicates that there is a gap and a need for guidelines for interventions that provide direction to social workers on how to conduct interventions for CABHA.

The purpose of this research is to examine existing intervention models for children affected by HIV and AIDS within South Africa and identify successful elements of existing models in order to develop guidelines for intervention to be used by social workers working with HIV-affected children.

### **1.3 PROBLEM STATEMENT**

The AIDS and AIDS crisis is one of the greatest health epidemics that has affected the world for over three decades. Global statistics reveal that the number of HIV-infected people has increased since a decade ago, from an estimated 34 million PLWH in 2012 (UNAIDS, 2012) to 38 million in 2022 (UNAIDS, 2022). Children are often left orphaned and without adult supervision when the parent or caregiver ultimately dies from HIV and AIDS-related illnesses.



The good news is that over the past decade, the global community and individual countries have progressed towards addressing the needs of HIV-affected children and families (Kidman & Heymann, 2016). Several interventions have been implemented across Africa to support children affected by HIV and AIDS (Betancourt et al., 2014; Bhana et al., 2010; Ssewamala et al., 2016). However, these interventions are implemented by various stakeholders independent of each, and the social worker's role is not clearly defined in these interventions. The Children's Act 38 of 2005 also does not give clear guidelines on how intervention should be implemented for children affected by HIV and AIDS. The Act only focuses on general HIV testing, counselling and confidentiality of children's HIV status, and HIV testing for foster care and adoption purposes. However, the children affected by HIV and AIDS can be identified as children in need of care and protection as defined by the Children's Act 38 of 2005, as the circumstances, they end up in due to parental/caregiver absence often warrants social work intervention. Because these children are vulnerable and in need of care, the participation of a social worker is very important, but the social worker's role is not always very clear. The National Strategic Plan (NSP) 2017-2022 by the government of South Africa provides a framework from which different stakeholders involved in HIV, TB and STI work can work and develop intervention programs (SANAC, 2017) but does not give clear guidelines for social work intervention. Therefore, this study's main aim is to develop guidelines for social work intervention with children affected by HIV and AIDS.

#### **1.4 RESEARCH QUESTIONS**

- What are the best practice models for interventions implemented for children affected by HIV and AIDS in Africa?

- What are the existing interventions implemented by organisations rendering services to Orphaned and vulnerable children and CABHA in the Cape Town Metropole?
- What are the experiences of social workers implementing interventions with CABHA?
- What are the guidelines needed by social workers when dealing with children who are affected by HIV and AIDS?

### **1.5 AIM OF THE STUDY**

The study aimed to develop guidelines for social work intervention with children affected by HIV and AIDS.

### **1.6 OBJECTIVES OF THE STUDY**

The objectives of the study were to:

- Identify and explore best practice interventions used with children affected by HIV for community-based care through a systematic review;
- Identify and describe the intervention models used when working with children affected by HIV and AIDS;
- Explore the experiences in using interventions aimed at children affected by HIV and AIDS;  
Develop guidelines for social work intervention with children affected by HIV and AIDS

### **1.7 METHODOLOGY**

The study made use of a qualitative research approach. Qualitative research explores and understands the meaning individuals or groups ascribe to a social or human problem (Creswell & Creswell, 2018). Qualitative research emphasises the meaning and understanding of the

problem being investigated. It also allows the researcher to study phenomena in their natural settings so that they can be interpreted in terms of the meaning people ascribe to them. Creswell and Creswell (2018) argue that qualitative research is used when a researcher needs a detailed understanding of an issue and wants to empower individuals to share their stories. The main aim of the current study was to gain a deeper understanding of the interventions used with children affected by HIV by various stakeholders and get the participants to share their experiences regarding these interventions. The qualitative research approach was deemed appropriate for the study as it contributed to gathering detailed information on interventions for children affected by HIV and AIDS, exploring the experiences of social workers in implementing these interventions and developing guidelines for social work interventions with these children.

### ***1.7.1 Study design***

The study design that was used was intervention mapping (IM), which is a framework that is often used in health promotion programs. IM is a six-stage process for designing theory and evidence-based health promotion programs to provide health promotion program planners with a framework for effective decision-making at each step of intervention planning, implementation and evaluation (Bartholomew Eldredge, et al., 2016). IM consists of various steps ranging from the design, intervention and implementation of the specific intervention. The purpose of IM is to “provide health promotion program planners with a framework for effective decision making at each step of intervention planning, implementation and evaluation” (Bartholomew Eldredge et al., 2016:3). IM consists of six steps as described by Bartholomew Eldredge et al. (2016:14) are: (1) Develop a logic model of the problem using a needs assessment (2) State program outcomes and objectives, (3) Develop program plan, and

design (including scope, sequence, change methods and practical applications), (4) Produce intervention (program production), (5) Program implementation plan (including materials and messages), (6) Develop an evaluation plan. The current study focused on three steps: needs assessment, developing program outcomes and objectives and developing a program plan and design.

The study was conducted in two phases. The first phase focused on a needs analysis, and the second phase focused on developing guidelines for social work intervention with children affected by HIV and AIDS. Each of the two phases covers the different objectives of the study.

### **1.8 SIGNIFICANCE OF THE STUDY**

The study provides insight into interventions used by social workers with children affected by HIV and AIDS. The study could have implications for (1) children affected by HIV and AIDS, (2) parents and caregivers, (3) social workers, (4) communities (5) the government. (1) The children affected by HIV and AIDS will benefit directly from interventions aimed at assisting them as there will be clear guidelines as to when and how to access these resources, and there will be less confusion. (2) Parents, and caregivers will know who and where to go to for assistance when there are issues related to the care of children affected by HIV and AIDS. (3) Social workers will know exactly what to do in different circumstances where children affected by HIV and AIDS are involved, and they will know the role of each stakeholder, which will produce better management of cases. (4) Communities will be able to take an active role in knowing what role they can play in supporting children and families affected by HIV and AIDS and will be able to access resources within their communities. (5) Government institutions will be able to integrate these guidelines into policies for better management and care of children affected by HIV and AIDS.

## **1.9 OUTLINE OF THE THESIS**

**Chapter 1:** This chapter is an introduction to the study. It provides an overview of the study, focusing on the background information on HIV and AIDS, a brief description of the methodology, the problem statement and the significance of the study.

**Chapter 2:** This chapter is a detailed literature review which starts by describing the extent of HIV and AIDS in the global, African and South African context. Furthermore, the impact of HIV on families and communities is explained to give context about how this leads to orphaned and vulnerable children that are affected by HIV and AIDS. The social worker's role in providing interventions is also described in relation to relevant legislation. The chapter concludes with an explanation of why there is a need for interventions for children with HIV and AIDS (CABHA). The theoretical framework that applies to this study is also explained in this chapter. The chapter describes Bronfenbrenner's Ecological Systems Theory as the theory that underpins the study, and the different levels of interaction, referring to the research topic to try and explain how this theory applies.

**Chapter 3:** The research methodology implemented in the study is explained in detail in this chapter. The research aims and objectives are explained as well as the research approach and design. The theory of IM research design used is explained, followed by a comprehensive explanation of how this design was implemented in the study. This is done by explaining the different phases and steps involved in the study. The last section presents the study's ethical considerations, reflexivity and trustworthiness.

**Chapter 4 – 6 :** The results of the study in Chapter 4 to Chapter 6 are written in article format.



**Chapter 4:** This chapter explains a systematic review of best practice interventions used with children affected by HIV for community-based care and support using a RE-AIM framework. The explanation focuses on how the systematic review was conducted by explaining the search strategy, inclusion criteria, study selection, data synthesis and analysis, and data extraction. The results are presented and explained in how they fit within the RE-AIM framework. The chapter concludes by discussing the results and their implications for practice.

**Chapter 5:** This chapter focuses on how a needs assessment for social work interventions for CABHA is done. The chapter explores the literature on challenges faced by CABHA and the role of social workers in interventions for CABHA. A detailed account of the research method and results on exploring the current interventions provided to CABHA by various organisations and the experiences of social workers in implementing interventions. The final section explains the limitation of the study and provides recommendations for practice and future studies.

**Chapter 6:** This chapter explains the different types of interventions for CABHA. The chapter presents the reflections given by different stakeholders on what the focus of the interventions is and who the major role players are in implementing these interventions. The social worker's role is described in relation to other role players.

**Chapter 7:** This is a detailed explanation of the development of guidelines for social work intervention for CABHA. The chapter discusses the methodology used in developing the guidelines, which is done by explaining the different stages of the development of guidelines. The theoretical framework used to develop the guidelines is explained, and the chapter concludes with a presentation of the guidelines.



**Chapter 8:** This chapter is a summary of the study. It focuses on providing conclusions of all the findings and linking these findings to the research aims and objectives. The chapter concludes with recommendations for future research.



## **CHAPTER 2**

### **CONCEPTUAL FRAMEWORK**

#### **2.1 INTRODUCTION**

This chapter focuses on the conceptual framework on which the study is based. The study is located within the framework of Bronfenbrenner's Ecological Systems Theory (EST) since children cannot be viewed separately from other systems they interact with, especially in relation to the intervention guidelines for social workers with CABHA. This chapter begins by providing a review of the literature that informs the study, which focuses on the extent of the HIV and AIDS epidemic in the global and South African context. The impact of HIV on the family and the child is also explained. The following section explains the social worker's role and refers to the framework for social work intervention and the policy framework that guides social work intervention with CABHA in South Africa. The last section discusses the theoretical framework that applies to the study by giving a historical background on the EST, followed by a detailed description of the different systems that make up the EST. The chapter concludes with a brief description of interventions for children affected by HIV and AIDS (CABHA).

#### **2.2 THE EXTENT OF THE HIV AND AIDS EPIDEMIC**

The HIV and AIDS epidemic is one of the major health challenges that negatively affects many individuals and their families. Before giving details about the extent of the HIV and AIDS epidemic, it is important to provide some globally recognised and accepted definitions. The World Health Organisation (WHO) defines HIV as the Human immunodeficiency virus, an infection that attacks the body's immune system, specifically the white blood cells called CD4

cells (WHO, 2022). Once the immune system is weakened, the person may become sick from opportunistic infections like TB, fungal infections, severe bacterial infections and some cancers and may eventually develop acquired immunodeficiency syndrome (AIDS). AIDS is a term that applies to the most advanced stages of HIV infection. It is defined by the occurrence of any of the more than 20 life-threatening cancers or “opportunistic infections”, so named because they take advantage of a weakened immune system (WHO, 2020).

### ***2.2.1 Prevalence of HIV infection***

The UNAIDS (2022) reports that the number of people living with HIV (PLWH) is estimated to be approximately 38 million globally in 2021, with more than half (54%) of them being women and girls. A total of 25,6 million of these PLWH are from Sub-Saharan Africa, accounting for 67,3 % of the global population of PLWH. This indicates that the high burden of HIV infections lies in the Sub-Saharan Africa region, which accounts for just over half of the HIV-infected population worldwide. Stats SA (2022) further reports that the total number of PLWH in South Africa is estimated at approximately 7,8 million in 2022, which is 20% of the global number of PLWH. UNAIDS (2022) explains that the reason for this increase can be attributed to the global increase of access to Anti-retroviral Treatment (ART), which results in an increased life span of PLWH.

Increased access to antiretroviral therapy has averted an estimated 12.1 million AIDS-related deaths since 2010, a 39% reduction in AIDS-related deaths (UNAIDS, 2022). Thus, these treatment programmes have changed the normal patterns of mortality across the globe as more people who are HIV positive can live longer and continue their normal lives living with HIV and AIDS. Similarly, South Africa also reported a consistent decline in AIDS-related deaths since 2007, from 278 741 to 85 796 AIDS-related deaths in 2022 (StatsSA, 2022). Despite the

worldwide response to the prevention and treatment of HIV and AIDS, the challenge remains that there is no cure for AIDS, and people still die from AIDS-related illnesses.

### **2.3 THE IMPACT OF HIV ON FAMILIES**

Traditional family structures and roles change due to the AIDS epidemic, and children end up being cared for by extended family members when their parents cannot care for them because of deteriorating health or death due to HIV-related (Nebunya, 2019; UNICEF, 2016). When children are left with no visible means of care, they most likely end up being alone or in the care of other family members, which puts a strain on the extended family. Furthermore, Breckenridge et al. (2019) explain that environmental changes may be difficult for children to adjust to as they try to navigate their new surroundings when they are ‘forced’ to live with extended family. It is acknowledged in the revised White Paper on Families (2021) that extended families carry much of the care burden for all those children affected and infected by HIV and AIDS (RSA, 2021). According to Nebunya (2019), the extended family is the primary and major source of social support for children in HIV-impacted communities. Some children are left in the care of grandparents who often struggle to keep up with the needs of a younger generation. Nebunya (2019) argues that extended family members, mostly grandmothers, are not willing or able to care for additional children. The White Paper (2021) also confirms that households where grandparents live with and are responsible for caring for their grandchildren, are prevalent in South Africa. This type of family is referred to as the skip generation.

In some instances, there may be children who must take care of ill parents or even siblings in the absence of a parent due to ill health. Children who live with an adult infected with HIV or suffering from AIDS-related illnesses experience social, emotional, and health vulnerabilities that overlap with, but are not necessarily the same as, those of orphans or other vulnerable

children (Goldberg & Short, 2016). The social, economic, and psychosocial impact of ‘orphanhood’ on children is compounded by the fact that many families live in communities already disadvantaged by poverty and have very limited access to basic services (Nebunya, 2019). Some children are left orphaned as parents or caregivers die due to HIV-related illness, which may contribute to child-headed households. A child-headed household is “a household without an adult caregiver, which is headed by the eldest or most responsible child who assumes parental responsibility” (RSA, 2021:180). These children have to take on the role of a carer instead of being the ones being taken care of.

#### **2.4 THE IMPACT OF HIV AND AIDS ON CHILDREN**

Although a steady decrease in the number of AIDS-related deaths has been reported (Stats SA, 2022), children are still losing parents due to HIV and AIDS-related illnesses, which profoundly impact children’s well-being. For the study, the term children, as stipulated in the Children’s Act (2005) and The United Nations Convention on the Rights of the Child (UNCRC, 1989), refers to any persons under the age of 18 years. Furthermore, it is important to explain what orphan means. According to Breckenridge et al. (2019), there is no universal definition used in South Africa for the term ‘orphan’. In this study, the definition provided in the Children’s Act (2005) will explain that an orphan refers to a child with no surviving parent caring for him or her.

An estimated 14.9 million children worldwide had lost one or both parents due to AIDS-related causes in 2021, and three-quarters of these children live in sub-Saharan Africa. (UNICEF, 2022). Stats SA (2022) further reports that AIDS-related deaths have remained prevalent in South Africa for over two decades. The death of a caregiver is a challenge for children, leaving



them orphaned, vulnerable to exploitation and without adequate adult support. These children are often referred to as orphaned, and vulnerable children (OVC), which is a term that refers to “orphans and other children made vulnerable by HIV and AIDS” (Department of Social Development, 2005:6). Thomas et al. (2021) further explain that OVC also includes those children who are HIV-positive, living without an adequate adult, living outside of family care, or is marginalised, stigmatised, or discriminated against.

Even if the caregiver is alive, residing with an HIV-infected or AIDS-sick adult is associated with vulnerability (Goldberg & Short, 2016), as the sick caregiver’s parenting capacity decreases when they are ill. A vulnerable child is described as “a child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance and which prevents the fulfilment of his or her rights” (DSD, 2005). Research shows that children living with HIV-infected or AIDS-ill adults often face a range of social, economic, academic and psychological problems resulting in a lack of access to opportunities that may enhance their well-being (Breckenridge et al., 2019; Kumakech et al., 2009; Sherr et al., 2016).

#### ***2.4.1 Children affected by HIV and AIDS***

It is common knowledge that children need a caregiver to provide for their needs. These caregivers can be the child’s parents or any adult responsible for providing for the child’s developmental needs. Children’s developmental needs that need to be catered for by parents or caregivers include health, education, emotional and behavioural development, identity, family and social relationships, social presentation and self-care (Parker & Bradley, 2004). It is, therefore, the responsibility of a parent or caregiver to ensure that these needs are provided for.



When a parent or caregiver becomes sick or dies of an HIV-related illness, the children are left vulnerable, and their developmental needs may not be addressed. HIV-related illness in parents has been shown to pose a series of indirect risks to child development. These risks include the need for children to shoulder household burdens due to reduced parental attention (Sherr et al., 2016). In some cases, children are left with no immediate support or families to take care of them. The Department of Social Development policy framework (2005) indicates that AIDS is reducing the pool of traditional caregivers and the number of breadwinners, resulting in increased poverty and reduced care for children.

When children are left with no visible means of support, alternative care must be provided. These children often end up in foster care or residential care facilities for children. However, placing a child in a residential care facility does not necessarily mean that all the child's developmental needs are catered for. A study conducted by Moses and Meintjies (2010) found little evidence of awareness in the children's homes of the psychological, behavioural and developmental effects of HIV on children. This means that while residential care facilities might be able to cater for a child's physical needs, they might not be aware of or have the capacity to cater to their emotional and behavioural development. Shang (2009:205) agrees that "children's physical and mental development is substantially impeded as they lose their caregivers and suffer psychological damage as a result of social exclusion". Linsk and Mason (2004) also identified CABHA as presenting with behavioural and emotional problems ranging from the adjustment to the parent's illness and deterioration to the stigma associated with HIV. Thus, placing orphaned children and those vulnerable due to HIV and AIDS in a residential care facility is not always the best option. Interventions should rather focus on attending to and understanding the emotional and behavioural problems first before anything else can be done.

Interventions directed at CABHA should protect children's rights at all times. The HIV and AIDS epidemic is a major catastrophe threatening South Africa's ability to meet its commitments to realising children's rights (Department of Social Development [DSD], 2005).

Section 28 (1) of the Bill of Rights states that every child has the right to; (b) family care or parental care or to appropriate alternative care when removed from the family environment and (c) basic nutrition, shelter, basic healthcare services and social services. As a result of HIV and AIDS, children are deprived of a chance to be normal because their right to parental love, care and nurturance is taken away when parents die from HIV-related illnesses. The impact of HIV and AIDS also takes away from children their right to basic care such as health, food and shelter, as the parents are not available to fulfil their duties and responsibilities when they are ill or have died from AIDS. DSD (2005) explains that the direct impact of HIV and AIDS on children occurs as material and non-material problems. The material problems are poverty, food security, education and health, and the non-material problems relate to welfare, protection and emotional, social and spiritual well-being. Previous research (Goldberg & Short, 2016) reports that HIV-infected caregiver is associated with a range of physical and emotional health outcomes in early and middle childhood and adolescence. This indicates that the HIV and AIDS epidemic affects people in all spheres of their lives, psychologically, physically, financially and spiritually.

HIV and AIDS pandemic has moved far beyond just being a health problem and affects various aspects and the general well-being of families. Barrett-Grant et al. (2003) link HIV and AIDS to unequal power distribution in society, with those who are the least powerful being the most at risk of contracting HIV. Kirst-Ashman and Hull (2012) identified this group of people as 'populations at risk' and further defined it as "those groups in society most likely to experience

and suffer consequences of discrimination, economic hardship and oppression” (p. 397). These people are often socially excluded in the communities because they differ from the more dominant and powerful segments of society. Some people who form part of the populations at risk are women, refugees, gays, lesbians, the elderly and children. Being infected or affected by HIV and AIDS further adds another element of stigma and discrimination to these groups that are already marginalised. Shang (2009) argues that the negative socio-economic effect experienced by families affected by HIV and AIDS is due not only to HIV and AIDS but also to the social discrimination and exclusion experienced by the affected families and their communities. To better understand the issues of HIV-related stigma and discrimination, Parker and Aggleton (2003) argue that it is important for us to think broadly about how different groups of people become socially excluded and to identify forces that create and reinforce exclusion in different settings. Very often, social workers work with these groups of people who are marginalised and socially excluded. The role of the social worker will be discussed in the following section.

## **2.5 FRAMEWORK FOR SOCIAL WORK INTERVENTION**

The Children’s Act 38 of 2005 defines a social worker as a person who is registered or deemed to be registered as a social worker in terms of Section 17 of the Social Service Professions Act 110 of 1978. Zastrow (2017: 48) describes social work as having four main goals, which are to:

- 1) enhance problem-solving, coping and development capacities of people;
- 2) link people with systems that provide them with resources, services and opportunities;
- 3) promote the effectiveness and human operation of systems that provide people with

resources and services; 4) develop and improve social policy; 5) promote human and community well-being.

It is clear from the description that social work facilitates social change and development amongst individuals, families, groups and communities. However, it should be noted that the definition of social work is very broad, making it necessary to look at it from a South African context. The social workers in South Africa are guided by various legislations depending on the context of their work. Therefore, the social worker's role must be discussed in detail to understand how their interventions address issues related to children affected by HIV and AIDS.

Within the South African context, Schenck et al. (2015) explain that when the democratic government was born in 1994, social work changed its paradigm towards social developmental social work, which emphasises empowering people through economic development, democratic participation in all issues relating to communities, taking ownership and social justice. This implies that social workers do not regard themselves as messiahs but as active participants who work collaboratively with clients during an intervention. It also means that clients are active participants in the social work intervention. Part of the duties of social workers is to work with people who are facing difficulties in their communities due to various social issues.

Social workers often work with those groups of people who are marginalised and discriminated against in the communities for several reasons. Various studies (Goldberg & Short, 2016; Parker & Aggleton, 2003; Shang, 2009; Varas-Díaz, 2019) have confirmed that it is common for people affected by HIV and AIDS to experience stigma and discrimination in communities. Varas-Díaz et al. (2019) argue that HIV and AIDS stigma remains a major global health issue

with detrimental consequences for people with HIV/AIDS. Children affected by HIV form part of the populations at risk as they often face stigma and discrimination in their environment due to parents and caregivers being HIV positive. To deal with issues related to stigma and discrimination, the social worker's role in such cases would be to provide intervention from an anti-oppressive practice model. According to Healy (2005), this model aims to provide more appropriate and sensitive services by responding to people's needs regardless of their social status. It is about acknowledging different power relations in society and working with an empowerment model (Dalrymple & Burke, 2006). The anti-oppressive practice "considers personal, institutional, cultural, and economic issues and how these influence individuals' behaviours and opportunities to grow into their full potential as persons living within these oppressive contexts" (Hines, 2012:23). Social workers need to make sure that in providing intervention from an anti-oppressive practice they focus on preventing PLWH from becoming at risk and try to alleviate problems experienced due to stigma or discrimination. Children affected by HIV form part of the populations at risk as they often face stigma and discrimination in their environment due to parents and caregivers being HIV positive. A study by Murphy et al. (2015) reported that the experience of stigma in children with HIV-infected parents was much higher than the other children whose parents were not HIV-infected.

Children whose parents are either sick or have died from HIV and AIDS-related illnesses are left vulnerable and in need of care, especially in the absence of a parent or caregiver. Section 150 in chapter 9 of the Children's Act identifies children as needing care and protection if (1a) the child has been abandoned or orphaned and is without visible means of support. Children affected by HIV and AIDS can thus be regarded as needing care as they may be abandoned or orphaned and vulnerable due to parental illness and may even end up in child-headed



households. The Children's Act (2005) requires that children in need of care be referred to a designated social worker for investigation and intervention.

### ***2.5.1 Legislation guiding social work intervention***

When children in need of care have been identified, social workers must intervene in such cases and ensure that the best care for them is provided by taking measures to assist them where necessary. The measures social workers need to take when working with children are guided by the Children's Act 38 of 2005. The Act describes the type of care in relation to a child needing care that should be provided to include, where appropriate, within available means, providing the child with a suitable place to live. These living conditions are conducive to the child's health, well-being and development and the necessary financial support. When it comes to intervention with children affected by HIV and AIDS, there is no one universal approach. To work effectively with children affected by HIV and AIDS, social workers must adopt various strategies and develop intervention programmes to assist the child holistically.

The Children's Act (2005) emphasises that the child's best interests are paramount in any decisions taken for the child. According to Chapter 2, subsection 7(k) of the Children's Act (2005), one of the factors that must be considered in the best interests of the child is that the child should be raised in a stable family environment and, if this is not possible, in an environment that is as close to a caring family environment as possible. This encourages the practice for children to be kept within their families and communities as it provides stability and a sense of security for the child. This should be one of the underlying principles when planning interventions for CABHA. One of the key strategic priorities for intervention with families recommended in the White Paper on Families (2021) also encourages 'family strengthening' rather than separating families.



The White Paper on Families is a policy framework on the family in South Africa that “prioritises the creation of the conditions for families to carry out the functions better they perform for their members and for society in and ensuring that families can overcome and manage stressful conditions” (RSA, 2021:7). It is described in previous versions (White Paper on Families, 2013:37), as a framework for working with families as it “helps service providers to analyse and interpret family-related issues and enable them to locate the family in the society”. Family strengthening, encouraged in the White Paper, focuses more on supporting families within their environments by providing them with the necessary resources and tools through capacity building. Family strengthening is defined as the “deliberate process of giving families the necessary opportunities, relationships, networks, and support to become functional and self-reliant” (White paper, 2013, p.3). Family strengthening focuses on empowering the family to take care of the child. According to Kirst Ashman (2017), this can be done by building on the strengths of the parents and caregivers so that they can effectively provide for and protect their children. The promotion of family life and the strengthening of the family, according to the White Paper (2021), are all central to the overall stability and general well-being of South Africa. The White Paper (2021) lists strategic priorities linked to the family-strengthening approach. These strategic priorities should be considered for planning and developing interventions for families and children affected by HIV and AIDS. These strategies suggest service providers: 1) promote family well-being, 2) Strengthen family relationships, and 3) treatment and support vulnerable families (RSA, 2021).

However, it is important to note that the White Paper on Families focuses on families in general and does not necessarily provide details about families where there is a parent who is HIV positive or how this affects the child. Interventions that have been done in the past (Bhana et

al., 2010; Ssewamala et al., 2016) involve various stakeholders, but the role of the social worker is neither visible nor clearly identified. These interventions were aimed at target groups such as children, grandparents, teachers and other people involved in the care of OVC in an attempt to provide psychosocial support to these children, including CABHA. These interventions used community and family-based models to improve the psycho-social well-being of children and were not specific to CABHA. It thus becomes important to explore the interventions within a South African context to determine the role of social work. This links to the current study's objectives which focus on identifying and describing the intervention models used by different stakeholders working with children affected by HIV and AIDS and also exploring the experiences of social workers using interventions with children affected by HIV and AIDS. To explore and understand interventions from a South African context, policies relating to interventions for children affected by HIV and AIDS will be discussed in detail.

### ***2.5.2 Policy framework for orphaned and vulnerable children in South Africa***

The national department of social development (DSD) of South Africa introduced a policy framework on orphans, and other children made vulnerable by HIV and AIDS in 2005 with the aim to “support, strengthen and mobilise children, families and communities to combat the effects of the AIDS pandemic” (DSD, 2005). The objective of the policy was to provide a framework to 1) ensure coordinated action at the national, provincial, district and local levels to realise the rights of orphans and other children made vulnerable by HIV and AIDS, their caregivers, families and communities; 2) ensure that legal, policy and institutional frameworks for the protection and promotion of the rights of affected children are implemented at all levels; 3) provide an overarching framework to support stakeholders in the development of

comprehensive, age-appropriate, integrated and quality responses to orphans and other children made vulnerable by HIV and AIDS.

The policy also outlines six key strategies that can be adopted by various stakeholders when implementing programs and interventions aimed at children made vulnerable by HIV and AIDS. These strategies provide guidelines for social workers and other stakeholders when developing programs. The strategies are as follows:

1. Strengthen and support the capacity of families to protect and care.
2. Mobilise and strengthen community-based responses for the care, support and protection of orphans and other children made vulnerable by HIV and AIDS.
3. Ensure that legislation, policy, strategies and programmes are in place to protect the most vulnerable children.
4. Assure access for orphans and children made vulnerable by HIV and AIDS to essential services.
5. Raise awareness and advocate for the creation of a supportive environment for OVC.
6. Engage the civil society sector and business community in playing an active role in supporting the plight of orphans and children made vulnerable by HIV and AIDS

The focus areas in these strategies highlight capacity building of families and communities, protection of children, linking to resources, advocacy and involvement of civil and business sectors. The emphasis is on the involvement of the family and the community to strengthen and create an environment conducive to children's lives. These strategies highlight the importance of keeping the child within his or her family and social environment and providing the necessary support to encourage optimal functioning. This links with the broker, advocate

and mobiliser roles of a generalist social work practitioner. A broker is described by Zastrow (2017:67) as when the social worker “links individuals and groups who need help (and do not know where it is available) with community services”. This role is linked to the fourth and sixth strategies, which require linking OVCs to essential services and involving civil and local businesses.

According to Kirst Ashman (2017), an advocate speaks on behalf of clients to promote fair and equitable treatment or gain needed resources. The advocacy role can be achieved through the third and fifth strategies that require representing children at the policy level and advocating for supportive environments. A mobiliser is described as one who identifies and convenes community members and resources to identify unmet community needs and effect changes for the better of their community. The first, second and sixth strategies all focus on mobilising for OVC needs to be met for the greater good of the child and community. As much as the focus is on family and community involvement, the policy’s primary focus is protecting the rights of orphans and children who are made vulnerable by HIV and AIDS.

A vulnerable child is described as a child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance and which prevents the fulfilment of his or her rights (DSD, 2005). This includes a child infected with HIV, a parent who is sick or dead from HIV-related illnesses, left with no means of support, abandoned or moves between different households, which means there is no permanent residence. Orphans form part of vulnerable children as the definition of an orphan according to the Children’s Act 38 of 2005 is ‘a child who has no surviving parent caring for him or her.’ This policy framework for OVCs is linked to the National Strategic Plan (NSP) of South Africa's government, which

addresses social and structural factors that drive epidemics (including HIV), influence their impact, and affect how the government cares for HIV-infected and affected people.

The challenge is that the policy framework on orphans and other children made vulnerable by HIV and AIDS was developed in 2005 and based on the NSP of that specific era (2000 to 2005). There has been no update on the policy as the NSP changes every five years to keep up with new developments in the field of HIV and AIDS. Since 2005, the NSP has been updated at least three times, and the extent of the HIV epidemic has changed since 2005. It thus becomes very important to consider these issues when implementing interventions, as it poses a potential problem if the policies that are supposed to guide interventions are not updated to keep up with new trends. The problem is that social workers will not make well-informed decisions when it comes to matters pertaining to orphaned and vulnerable children if they use outdated information.

Furthermore, intervention programs might not meet the children's needs as the programs' content will be based on information that might not be relevant, and the needs might change over time. New policies, or at least updated policies, need to keep up with the times and trends in relation to the government's NSP. The latest NSP for 2017 to 2022 will be discussed further below.

### ***2.5.3 The National Strategic Plan for HIV, TB and STIs 2017-2022 in South Africa***

The NSP is a guide developed in South Africa as a multi-stakeholder response to HIV, Tuberculosis (TB) and sexually transmitted infections (STIs). The plan seeks to address different factors contributing to high infection rates, illness and death due to these infections, as mentioned above. The NSP is an initiative that is facilitated by the South African National



AIDS Council (SANAC), the national department of health (DOH), as well as the Civil Society Forum (CSF). The forum consists of representatives from the different sectors in the community, such as sports, arts and culture; women; disability; traditional leaders; youth; Non-Governmental Organisations (NGOs); sex workers and LGBTI. According to SANAC (2017), the NSP builds on the significant progress achieved to date, addresses gaps identified during the past five years and seeks to scale up best practices to ensure quality and innovation underpins service provision. The NSP provides a framework from which different stakeholders involved in HIV, TB and STI work can work and develop intervention programs. It also provides a framework for monitoring and evaluating services within a five-year period. The NSP has eight goals, and clear objectives and activities support each goal to realise them. One of the goals of the NSP that is closely linked to the study is ‘to reach all key and vulnerable populations with customised and targeted interventions’ (SANAC, 2017). Vulnerable populations are described in detail by SANAC in relation to this goal.

It is important to focus on describing vulnerable populations as it is relevant to the current study. SANAC (2017) identifies the vulnerable populations for HIV and STIs as adolescent girls and young women, children including OVC, people living in informal settlements, mine workers, mobile populations, migrants and undocumented foreigners, people with disabilities, other Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) populations. It is clear from the description given above those children affected by HIV, and AIDS are also part of vulnerable populations. The NDP suggests a multi-sectoral approach in interventions aimed at CABHA. This means that the management and care of children affected by HIV and AIDS should not be restricted to a single service provider but should be facilitated by various organisations interested in promoting children's well-being.



One of the objectives of NSP is to ‘increase engagement, collaboration and advocacy of key and vulnerable populations in the development and implementation of social and health support activities.’ This supports the suggestion made in the chapter that interventions should be community-based and collaborative in any matter concerning children (Thurman et al., 2017; Yates et al., 2010). The Children’s Act 38 of 2005 also supports the collaboration of stakeholders in matters involving the child. The general principle no 10 in Chapter 2 of the Act states that every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration. The Act also makes provision for the child's best interests to be considered in all proceedings, actions and decisions by any organ of the state in any matter concerning a child in general. This is in line with article 12 of the United Nations Convention on the Rights of the Child, which stipulates that “States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” (UNCRC, 1989).

The above discussion clearly indicates that social workers must ensure that they protect the child's best interests when planning and implementing interventions, as stated in the Children’s Act 38 of 2005. The policy framework currently provides guidelines for social workers is outdated, as it was developed in 2005. Since then, a lot of developments and changes in policies in relation to the management of HIV and AIDS have occurred. It is also important to note that children affected by HIV and AIDS cannot be helped in isolation from their families and their environment, which means that the focus of interventions should be on family strengthening rather than separating families.

## **2.6 BRONFENBRENNER'S ECOLOGICAL SYSTEMS THEORY**

To provide proper intervention to children affected by HIV and AIDS, social workers must ensure that they provide holistic services, including the child's family and other relevant people in the child's environment. Children and the problems they experience should not be viewed in isolation but should be looked at in the context of the environment in which they interact with. Kirst-Ashman (2017) argues that in recent years, the emphasis on children has shifted from focusing on the child alone to the family and the social environment. This shift aims to strengthen the child's environment to "provide a nurturant, supportive setting in which children can grow and thrive" (Kirst-Ashman, 2017:288). When planning their intervention with CABHA, it becomes necessary for social workers to consider the impact of environmental factors on the child's functioning. Given the above factors, the study is thus located within Bronfenbrenner's Ecological Systems Theory, which is discussed in the next section.

The reason for choosing this theory is that Bronfenbrenner's theory is, as explained by Eriksson et al. (2018), appealing as a conceptual tool for guiding interventions within the field of public health. EST looks at the different systems affecting the lives of individuals and how each of the systems interacts with, affects and influences the others (Milner et al., 2015). At the centre is the person or child with individual gender, age, health, inherent characteristics, and abilities. Paquette and Ryan (2001) further explain that EST looks at a child's development within the context of the relationship system that forms his or her environment.

### ***2.6.1 History of the Ecological Systems Theory***

American psychologist Urie Bronfenbrenner developed the Ecological Systems Theory (EST) in the 1970s to explain how the social environment affects children's development. The original work of Bronfenbrenner in relation to human development focused on the direct or indirect

impact of the enduring environment on the child. Bronfenbrenner (1974) described the enduring environment as the child's ecology, which consists of two circular layers, with the first overlaid upon the second. The first layer is regarded as the upper, most visible layer in the immediate setting containing the child's home, school, street, playground etc. The second layer is the supporting layer, where “the immediate setting is embedded, limits and shapes what can and does occur within the immediate setting” (Bronfenbrenner, 1974:2).

Bronfenbrenner was critical of previous theories of child development. Bronfenbrenner (1974) argued that the majority of earlier studies were "unidirectional," which means that they focused on the effects of A on B (for example, a stranger or mother with a child) rather than considering any potential effects of the child or any other third party on the stranger or mother. Furthermore, Bronfenbrenner (1975:439) argued that researchers “have little conception or knowledge of how environments change, and the implications of this change for the human beings who live and grow in these environments.” In developing the EST further, Bronfenbrenner (1977) focused on explaining the connection between reality and research in human development and proposed merging of the naturalistic and the experimental approaches to human development, which he named ‘the ecology of human development’. The ecology of human development is described as “the scientific study of the progressive, mutual accommodation, throughout the life span, between a growing human organism and the immediate changing environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the larger social contexts, both formal and informal, in which the settings are embedded” (Bronfenbrenner, 1977:514).

### *2.6.1.1 The evolution of the Ecological Systems Theory*

The theory evolved from an ecological approach to human development during the initial phase (1973–1979), followed by a stronger emphasis on the role of the individual and developmental processes during 1980–1993 and finally, in the last phase (1993–2006), the focus was on Process–Person–Context–Time model (Rosa & Tudge, 2013).

Bronfenbrenner started to develop his ecological theory as a fresh theoretical approach to comprehending human development, and this theory underwent significant changes since its inception in the late 1970s (Eriksson et al., 2018). Bronfenbrenner's EST evolved over a period of time, and the evolution has been described in different phases (Rosa & Tudge, 2013). Bronfenbrenner (1975) argued that to develop and survive, the fit between the individual and their environment must also be even closer. Bronfenbrenner described the ecological environment as composed of systems at four different levels. These were the microsystem (relations between the individual and the immediate environment), mesosystem (interrelations between major settings containing an individual), exosystem (social structures and major institutions of the society) and macrosystem consisting of the world of work, the mass media and public agencies (Eriksson et al., 2018). Bronfenbrenner believed that to comprehend and explain a developmental outcome, it was imperative to examine the makeup of various ecological systems and interactions between, within, and between these systems (Eriksson et al., 2018).

The second stage focused on adding biology and chronosystem into the ecological framework. Bronfenbrenner and Ceci (1994) argued that human development involves interactions between a person's biological, psychological, and environmental factors. The achievement of human potential necessitates an intermediary mechanism that links the internal and external

worlds in a two-way process that takes place over time. It is during this stage that the fifth level, chronosystem, was added, and according to Eriksson et al. (2018), Bronfenbrenner wanted to investigate how changes over time, not only within the person but also in the environments in which that person is found, may affect a person's developmental outcomes.

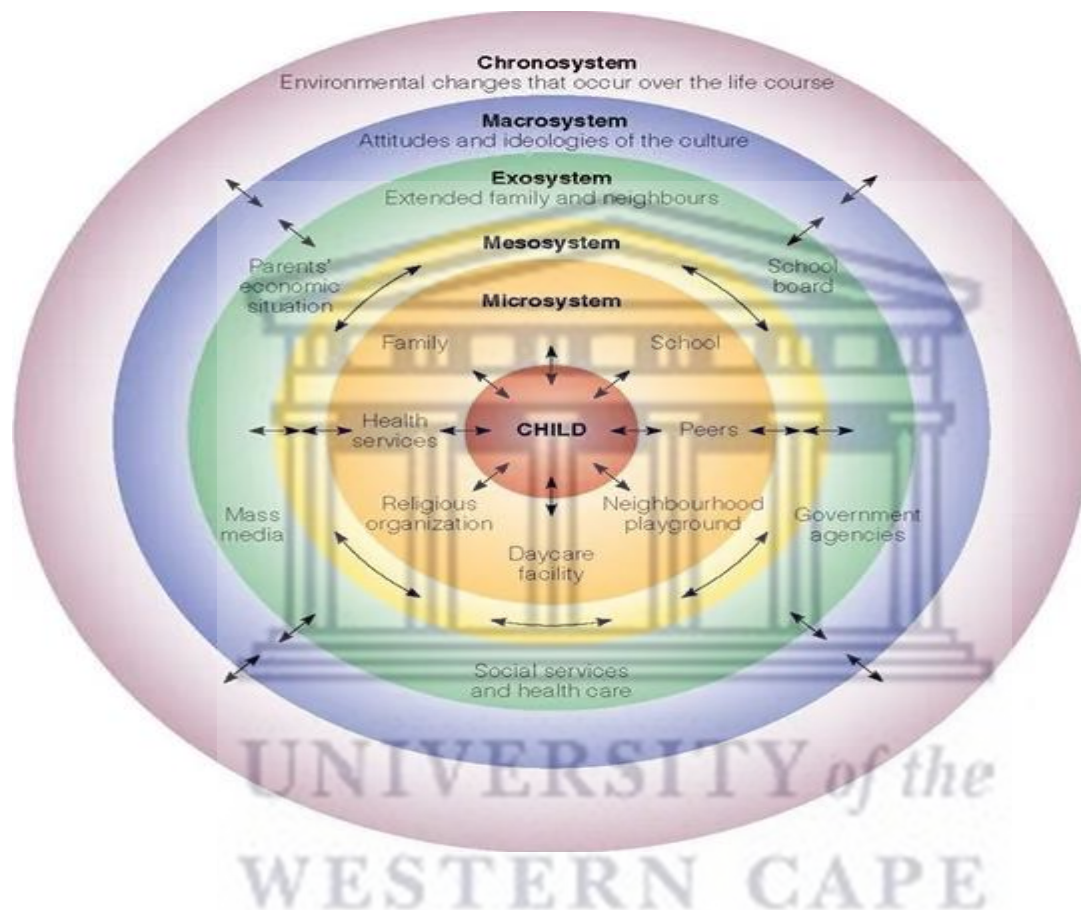
The third stage was the Process–Person–Context–Time (PPCT) model in the mid-1990s–2006, which introduced the term proximal processes. Eriksson et al. (2018) explain that proximal processes involve reciprocal interaction between the developing individual and other significant persons, objects and symbols in his/her immediate environment, and these processes could involve activities between parents and child and child and child, such as playing, reading and learning new skills. Eriksson et al. (2018:420) further explain that during this stage, Bronfenbrenner reconceptualised the microsystem and elucidated that “proximal processes operate within microsystems and involve interaction with three features of the immediate environment: persons, objects and symbols.”

### ***2.6.2 Levels of the Ecological Systems Theory***

The work of Bronfenbrenner, according to Guy-Evans (2020), looked beyond individual development, taking into account wider influencing factors and the context of development. Bronfenbrenner's ecological systems theory views child development within the context of the system of relationships that form his or her environment and defines complex “layers” of the environment, each affecting a child's development (Paquette & Ryan, 2001). Each system has its values and rules and interacts with the systems on either side of it, causing effects which travel both ways between the macro and the personal (Milner et al., 2015). Christensen (2010) explains that to understand the individual, it is not enough to describe them in the context of their family (the micro context); we must also take into account how the various systems



interact with the individual and with each other (the meso context) as well as their context of daily living (macrosystem). A graphic representation of the EST is presented in figure 2.1, and a detailed description of the five environmental systems will be discussed in the next section



**Figure 2.1 Bronfenbrenner's Ecological Systems Theory**

Source: (Guy-Evans, 2020)

### 2.6.2.1 Microsystems

Bronfenbrenner (1977) describes the microsystem as containing relations between the individual and the immediate environment surrounding the individual, such as the home, school and childcare environments. It is a venue for the child's initial learning about life & world,



developing mutuality with significant others and building trust (Milner et al., 2015). The microsystems refer to the child's immediate environment of people and places such as family, peers, school, church and childcare environments. According to Paquette and Ryan (2001), at this level, the impact of the relationship is in two directions - both away from the child and toward the child. For example, a child's parents may affect his beliefs and behaviour, and the child also affects the behaviour and beliefs of the parent. Any change in one individual within a family is likely to influence the entire system and may even lead to changes in other members (Pfeiffer & In-Albon, 2022). Guy- Evans (2020) agrees that interactions in a microsystem are reciprocal, indicating that a child can be impacted by others in their surroundings and has the power to alter the attitudes and behaviours of others as well.

The child's family forms part of the microsystem as these are the people in the child's immediate environment. Hepworth et al. (2010) describe the family as a dynamic and transactional social system in which each constituent and sub-systems interact in a predictable and organised fashion. The different parts of the family system are considered connected to and are in transaction with each other. According to Sutphin et al. (2013), the family system can be further divided into subsystems, defined as systems within a larger system with its own boundaries and norms. Hepworth et al. (2010) further elucidate that families can be divided into subsystems such as parents, siblings, grandparents, and extended biological or non-biological kin who join together to perform various family functions. This implies that the different parts of the family system interact with each other to contribute to the overall functioning of the family.

It is quite common in South Africa for extended family members to take care of orphaned children after one or both parents pass away or when the whereabouts of the child's last living

parent is unknown (Breckenridge et al., 2019). For orphaned children in HIV-impacted communities, the extended family system is still the primary and major source of social support (Nabunya, 2019). The White Paper on families (2021:9) confirms this and states that “the family remains an integral part of South African society and its continued existence is dependent on vibrant and well-functioning communities”. Milner et al. (2015) argue that a common source of problems lies in boundary breaches between the subsystems, which can ultimately result in dysfunctional families. Internal boundaries are disturbed by HIV-related illness and/or death of the parent as the roles of the children and other family members change. In a skip-generation family, the grandparents suddenly become the parents. In child-headed households, the elder child either becomes the carer to the parent or a ‘parent’ to the siblings. In planning interventions for CABHA, social workers need to be mindful of the different systems that interact with the child within the micro context and work on a framework that includes families and significant others in the child’s immediate environment.

#### *2.6.2.2 Mesosystem*

The mesosystem comprises interrelations between major settings containing an individual, such as relations between home and school and home and peer group (Bronfenbrenner, 1977). It refers to the connections between parts of the microsystem and the relationship between some microsystems (Milner et al., 2015). In the mesosystem, a person's various microsystems interact and exert influence over one another rather than operating independently (Guy-Evans, 2020). Examples are parent-teacher relationships (the connection between the child’s teacher and the parents), and the relationship between church and neighbourhood. Visser (2015) argues that CABHA is vulnerable as the illness and death of parents often result in loss of emotional, financial and material support, affecting their school attendance and, ultimately, academic

performance. Children with ill parents, specifically HIV/AIDS-related illnesses, may need to drop out of school or fall behind due to caring for an ailing parent (Andrews et al., 2006). Breckenridge et al. (2019) explain that assisting caregivers in understanding the importance of continued education could help improve the child's attendance and completion rate in school. Suppose the child's parents and teachers have a good relationship. In that case, this should positively affect the child's development, compared to negative effects if the teachers and parents do not get along (Guy-Evans, 2020). This shows that even though there may not be direct interaction with the child, the interaction between the teacher and parent can positively influence the child. Therefore, interventions for CABHA need to consider that the interactions between macrosystems influence a child's experiences and behaviour.

#### 2.6.2.3 Exosystem

The exosystem refers to a larger social system in which the child does not operate directly. The environments directly affect the child even though s/he has no direct contact with them (Milner, Myers, & O'Byrne, 2015). This involves links between a social setting in which the individual does not have an active role and the individual's immediate context (Christensen, 2010). Paquette and Ryan (2001) argue that even though the child may not be directly involved at this level, s/he does feel the positive or negative force involved with the interaction with his own system. This means that some parts within the microsystem are usually the ones interacting with the exosystem, and these interactions impact the child. These social structures do not themselves contain the developing person but impinge upon the immediate settings in which that person is found and influence what is going on in these settings (Bronfenbrenner, 1977). Examples of the exosystem are major institutions of society such as the parental workplace,

the mass media, public agencies and community-based family resources, neighbourhood, and parents' friends.

According to Guy-Evans (2020), these situations do not include the child and are not part of their everyday lives, but they nonetheless have an impact on them. These systems do not themselves contain the developing person but impinge upon the immediate settings in which that person is found and influence what is going on in these settings (Bronfenbrenner, 1977). The social work agencies and community-based interventions form part of the exosystem, where decisions are made on whether CABHA requires care and the type of care needed. Schenck (2009) argues that community interventions aim to build caregiver and community capacity by enhancing traditional kinship- or community-based support systems. Very often in Sub-Saharan Africa, according to Nabunya et al. (2019), relief for orphaned children and their families comes from informal sources of support such as neighbours, friends, teachers, other community members and non-government institutions, including churches, civil society or community-level informal groups –where they exist. The interactions within the exosystems may directly impact the child as the social worker, community members, and other stakeholders engage in discussions and make decisions about interventions for children. Even though they may not directly interact with the child, the decisions that are made have a direct impact on the child.

Nabunya et al. (2019) argue that as HIV caregivers continue to die, the number of orphaned children continues to increase, putting a strain on the extended family system that traditionally provided care and support to orphaned children. Milner et al. (2015) argue that the most important aspect of the difficulties associated with change is how they are handled. These changes in the case of an incapacitated parent may result in the children being cared for by

grandparents, thus changing the structure of the family to a 'skip generation' family, which White Paper defines on Families (2021) as households where grandparents live with and are responsible for caring for their grandchildren. In some instances where there is statutory social work intervention, the children may end up in foster care or residential facilities. All these changes come with new roles and rules to which the children need to adapt.

#### *2.6.2.4 Macrosystem*

This macrosystem is considered the outermost layer in the child's environment. It consists of the blueprints of a particular society, such as laws and regulations, but also unprinted rules and norms (Bronfenbrenner, 1977). These include national and international agencies, social ideologies, cultural values, laws, politics, attitudes, and beliefs that affect and cascade throughout other layers. The effects of larger principles defined by the macrosystem have a cascading influence throughout the interactions of all other layers. Children's vulnerabilities vary by individual, household, and community characteristics (Goldberg & Short, 2016), which means that social workers need to be aware of the child's context, including factors like culture, religion and values that the child subscribes to. Before embarking on community engagement, the social worker needs to understand what type of communities they are dealing with and the community's rules, norms and standards. This will ensure that the intervention is contextually relevant and does not clash with community values, which could ultimately negatively affect and not benefit CABHA. Taking into account the impact of macrosystems on CABHA is more likely to lead to successful interventions

#### *2.6.2.5 Chronosystem*

This system encompasses the dimension of time as it relates to a child's environment. This system includes all the environmental changes that occur throughout a person's life and



influence development, such as major life transitions and historical events (Guy-Evans,2020). It relates to changes over time, not only within the person but also in the environments in which that person is found (Eriksson, Ghazinour, & Hammarstrom, 2018). Guy-Evans (2020) explains that elements within this system can be either external, such as the timing of a parent's death, or internal, such as the physiological changes that occur with a child's ageing. This system is relevant to CABHA as they experience quite a number of changes in their environment due to parental illness or death. CABHA naturally suffer the grief of seeing their parents struggle with a long illness and the subsequent death of their parents (Chitiyo, Changara, & Chitiyo, 2008). Carer ill health has been proven in several studies (Bradshaw et al., 2002; Breckenridge et al., 2019; Sherr et al., 2014) to play a significant role in children's psychological, physical, spiritual and economic well-being as it negatively affects the parent's ability to take care of their children. As children get older, they may react differently to environmental changes and be more able to determine how that change will influence them. Therefore, interventions need to take note of important life events in the children's lives and the impact these have on their day-to-day functioning.

## **2.7 CONCLUSION**

This chapter provided the conceptual framework for the study. The focus of the chapter was on providing background literature on the extent of the HIV and AIDS epidemic and its impact on families and children. This highlighted the fact that there are currently more people living with HIV than more than a decade ago, and the leading cause of death is still due to HIV-related illnesses. The result is children who are often left orphaned and vulnerable to parental death. A framework for social work intervention was provided, which identified relevant legislation and policy framework that informs social work practice when it comes to intervention with



children affected by HIV. The chapter highlighted the need for social workers to link interventions with relevant policies relating to children and families. Further emphasis was placed on Bronfenbrenner's Ecological Systems Theory (EST) as the relevant theoretical framework that informs social work intervention since CABHA cannot be assisted independently of other systems within their environment. The chapter emphasised the impact that parental HIV illness has on children at all levels of the EST and the need for practitioners to consider these when planning interventions for CABHA.



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## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1 INTRODUCTION

The chapter provides an explanation of the research methodology that was used in conducting the study. The first section provides an overview of the aim and objectives of the study. The second part focuses on describing the research approach and the study's research paradigm. An explanation of intervention mapping as chosen for the study is given, and the different phases of this design, followed by a description of how the phases were implemented, is given. A further explanation of each step is given, which focuses on the research setting, population and sampling, data collection and analysis in the steps. The chapter concludes with a presentation of the study's ethical considerations, reflexivity and trustworthiness.

#### 3.2 AIMS AND OBJECTIVES

The study aimed to develop guidelines for social work intervention with children affected by HIV and AIDS (CABHA). The objectives of the study were to:

- 1:** Explore best practice interventions used with children affected by HIV for community-based care and support in three African countries through a systematic review.
- 2:** Identify and describe the intervention models used by various organisations working with children affected by HIV and AIDS.
- 3:** Explore the experiences of social workers using interventions aimed at children affected by HIV and AIDS.
- 4:** Develop guidelines for social work intervention with children affected by HIV and AIDS.

### **3.3 RESEARCH METHODOLOGY**

The research approach applied to this study is the qualitative research approach. Qualitative research explores and understands the meaning individuals or groups ascribe to a social or human problem (Creswell & Creswell, 2018). It is widely used to collect and understand specific information about a particular population's behaviours, opinions, values, and other social aspects (Dubey & Kothari, 2022).

#### ***3.3.1 Qualitative Research Approach***

The focus of the qualitative research approach is studying phenomena in their natural settings, which is what the current study aimed to achieve. Qualitative research emphasises the meaning and understanding of the problem being investigated. According to Merriam and Grenier, (2019), qualitative research focuses on how people understand and experience their world at a particular time and context. Leedy and Ormrod (2019) add that a qualitative research approach is used to answer questions about the complex nature of phenomena. To describe and understand the phenomena from the participant's point of view. The focus of the current study was to explore the experiences of the research participants in the different stages of the research process and explain the meanings that participants give about the research problem. Creswell and Creswell (2018) highlight a few important characteristics of qualitative research, and these are that the research takes place in the natural setting; relies on the researcher as the instrument for data collection; employs multiple methods of data collection; is both inductive and deductive; is based on participants' meanings; includes researcher reflexivity and is holistic. Some of these characteristics are explained further below, and their applicability to the study is also discussed.

### *3.3.1.1 Natural Setting*

One of the characteristics the current research has fulfilled, and one important feature, relates to qualitative research being done in a natural setting. Qualitative researchers tend to collect data in the field at the site where participants experience the issue or problem under study (Creswell & Creswell, 2018). This enables phenomena to be studied in their natural settings and interpreted in terms of the meaning people ascribe to them. Studying phenomena in their natural setting allows face-to-face interaction, often extending over a prolonged period, which took place in the current study. The first and second stages of data collection in the first phase consisted of face-to-face interviews with the participants over a long period, allowing them enough time to be comfortable in their natural setting. It was important to ensure that the participants were in their natural setting. Hence the venue and time for the interviews were at the discretion of the participants. This up-close information gathering done by talking directly to people and seeing them behave and act within their context is a major characteristic of qualitative research (Creswell & Creswell, 2018). The qualitative research approach facilitates the use of own words by participants and makes it easier for people to reflect on their meanings and understandings of the phenomena (Robson & McCartan, 2016). Qualitative research focuses on providing detailed descriptions of the participants' written or spoken words. The findings chapter of this study gives detailed accounts of the participants' reflections and provides direct quotes where necessary.

### *3.3.1.2 Inductive Data Analysis*

Another important feature of qualitative research, identified by Bryman (2016) and Creswell and Creswell (2018), which the current study has is inductive data analysis. Creswell and Creswell (2018:181) argue that “qualitative researchers typically work inductively, building patterns, categories, and themes from the bottom up by organising the data into increasingly

more abstract units of information”. This is further confirmed by Thomas (2021), who explains that induction involves a bottom-up approach which starts with specific observations, detects patterns and regularities, formulates a tentative conclusion and finally develops general conclusions. The inductive process involves working back and forth between the themes until a complete set of themes is established (Creswell & Creswell, 2018). After identifying themes, qualitative researchers often use a deductive mode to confirm or alter the theme with additional data (Fouché, Strydom, & Roestenburg, 2021). This is evident in the current study as the data analysis in both phases involved thematic data analysis. The process of thematic analysis involved making sense of the information gathered by looking for patterns and similarities in the participants’ responses and making a conclusion based on the themes identified. This process also involved working back and forth between the themes and categories until a comprehensive set of themes was established. A detailed explanation of the data analysis for each stage is provided further in the chapter under the different stages of the research process.

### *3.3.1.3 Participants’ Meanings*

Another characteristic of qualitative research relates to the interpretation of participants’ meanings. The goal of qualitative research is to discover the meaning that participants have about a problem or issue rather than the meaning that researchers bring to the study or what is expressed in the literature (Creswell & Creswell, 2018). Fouché et al. (2021) explain that the qualitative approach can be regarded as an interpretative approach that is holistic and aimed at comprehending social life and the significance that people place on it. “In its broadest sense, a qualitative research approach refers to research that elicits participants’ accounts of meaning, experience, or perceptions” (Fouché et al. (2021:42). The current study focused on gathering information on the perspectives of service providers and experiences of social workers in



implementing interventions for CABHA. The qualitative researcher is therefore concerned with describing and understanding rather than explaining or predicting human behaviour, with observation rather than controlled measurement, and with the subjective exploration of reality.

The idea that meaning is socially constructed by individuals interacting with their world is central to understanding qualitative research (Merriam & Grenier, 2019). Qualitative research is about how individuals experience and interact with their social world and the meaning they ascribe to it. It is based on an interpretive (or constructivist) perspective embedded in the qualitative approach (Merriam & Grenier, 2019). This is often referred to as the research paradigm.

### **3.4 RESEARCH PARADIGM**

A paradigm is described by Fouché et al. (2021) as the framework through which we make sense of the world and prescribes what is acceptable within a community of practice. Fouché et al. (2021) recommend that research be conducted within a specific paradigm and that researchers grasp the nature of their selected paradigm and use it to substantiate the methodology and methods they ultimately select. A paradigm is a basic belief system and theoretical framework with assumptions about ontology, epistemology, methodology and methods (Rehman & Alharthi, 2016). These four basic components of a research paradigm are briefly discussed in the next paragraph.

Ontology refers to the views on the nature of reality. It is the professional stance in relation to the nature of things or how reality is interpreted in the professions (Fouché, Strydom, & Roestenburg, 2021). Epistemology refers to the nature of knowledge and the process by which knowledge is acquired and validated (Rehman & Alharthi, 2016). It is concerned with “the

nature and forms [of knowledge], how it can be acquired and how communicated to other human beings” (Cohen et al., 2007: 7). Methodology is a philosophical and scientifically informed way to solve the research problem systematically and a framework that informs all designs, methods and techniques that will be used in conducting research (Fouché, Strydom, & Roestenburg, 2021). The methodology is a step-by-step process of conducting the research study from start to finish.

The research paradigm that underpins this study is the constructivist paradigm which, according to Creswell and Creswell (2018), is often combined with interpretivism. Creswell and Creswell (2018) explain that social constructivists believe that individuals seek an understanding of the world in which they live and work. The assumption is that people's reality is formed through their interaction with the community, their world, and their shared interpretation of it (Peter Willett, Hepworth, Grunewald, & Walton, 2014). The focus of phase one of the research was on obtaining detailed descriptions from organisations and social workers about their experiences of interventions for CABHA. The responses gathered were based on the different organisations and social workers' interaction with CABHA, the families and the communities and their interpretation of these interactions. The constructivist paradigm focuses on the individual's learning that takes place because of their interactions within a particular social context. Social constructivism assumes that knowledge, no matter how it is defined, is in the heads of persons and that the individual has no alternative but to construct what he or she knows based on his or her own experience (Kemp, 2012). This implies that individuals construct knowledge based on their pre-existing information and the information they interact with to make judgements. This applies to both phases of the research process, specifically to phase two of the study. Stage two is where the participants of the Delphi

workshop were experts and stakeholders with varying degrees of experience in research and interaction with CABHA at the individual, group and community levels. These participants were tasked with discussing guidelines for social workers working with CABHA. They all came with pre-existing information about CABHA and interventions, which they used to make judgements in interpreting the guidelines and making recommendations. Therefore, the constructivist research paradigm is appropriate for the current study as it emphasises the understanding of the social world through an examination of the interpretation of that world by its participants.

Therefore, Creswell and Creswell (2018) argue that the research's goal within the social constructivism paradigm is to rely as much as possible on the participants' views of the situation being studied. The current study relied on the participants' views in all stages of the data collection process and the explanations they gave based on their interaction with the children affected by HIV and AIDS. During stage 2 of the data collection process, the participants had to describe the intervention models for children affected by HIV and AIDS that they used in the organisations. Stage 3 also focused on descriptions given by the social workers of their experiences of using interventions with children affected by HIV and AIDS. This means that the interpretation of the results is not based on the researcher's interpretation but on the explanations given by the participants based on their experiences.

### **3.5 RESEARCH DESIGN OF THE CURRENT STUDY**

The study made use of an intervention mapping (IM) research design which “facilitates a stepwise process to guide researchers through the development and planning of interventions by combining scientific knowledge and opinions from stakeholder” (Oude Hengel et al., 2014:2). IM is a six-stage process for designing theory and evidence-based health promotion

programs to provide health promotion program planners with a framework for effective decision making at each step of intervention planning, implementation and evaluation (Bartholomew et al., 2016). IM consists of various steps ranging from the design, intervention and implementation of the specific intervention.

IM consists of six steps, as described by Bartholomew et al. (2016:14), where the program planner has to (1) Develop a logic model of the problem using a needs assessment, (2) State program outcomes and objectives, (3) Develop program plan and design (including scope, sequence, change methods and practical applications), (4) Produce intervention (program production), (5) Program implementation plan (including materials and messages) (6) Develop an evaluation plan. Bartholomew et al. (2016) and O'Connor (2021) argue that the process of applying IM steps is not linear in practice. The steps of IM can be adjusted to fit the context of the research project and program being developed. This means that in some instances, not all the steps of the IM process may be applied, but the steps are used as a guide by program planners.

The interpretation of IM design has evolved over the years, and different scholars (Bartholomew et al., 2006; Bartholomew Eldredge et al., 2016; Oude Hengel et al., 2014) use different words to describe the steps, and at times there is overlap in the information of the different steps. The current study implemented an adapted version of the IM to fit the context of the study. It focused on steps 1, 2 and 3, which are the needs assessment, developing program outcomes and objectives and developing a program plan and design. A detailed explanation of the implementation of the IM design for the current study will be discussed further in the chapter. A graphic representation of the steps of IM is presented below, as presented by

Bartholomew et al. (2006) and followed by the discussion of the steps applicable to the current study.

**Table 3. 1 Intervention Mapping Steps**

<b>STEP</b>	<b>TASKS</b>
<b>Step 1</b> Needs assessment	<ul style="list-style-type: none"> <li>- Plan needs assessment</li> <li>- Assess physical environment behavioural determinants and organisational factors</li> <li>- Establish program objectives</li> </ul>
<b>Step 2</b> Program outcomes and objectives,	<ul style="list-style-type: none"> <li>- Specify expected outcomes for behaviour and environment</li> <li>- Specify performance objectives</li> <li>- Select determinants</li> </ul>
<b>Step 3</b> Program plan and design	<ul style="list-style-type: none"> <li>- Review program ideas with stakeholders</li> <li>- Identify theoretical methods</li> <li>- Choose program methods</li> <li>- Select/ design strategies to deliver methods</li> </ul>
<b>Step 4</b> Program production	<ul style="list-style-type: none"> <li>- Refine program structure and organisation</li> <li>- Prepare plans for program materials</li> <li>- Draft messages, material and protocols</li> <li>- Pre-test, refine and produce materials</li> </ul>
<b>Step 5</b> Program implementation plan	<ul style="list-style-type: none"> <li>- Identify potential program users</li> <li>- State outcomes and performance objectives for program use</li> <li>- Design implementation interventions</li> </ul>
<b>Step 6</b> Evaluation plan.	<ul style="list-style-type: none"> <li>- Write and process evaluation questions</li> <li>- Develop indicators and measures for assessment</li> <li>- Specify evaluation design</li> <li>- Complete the evaluation plan</li> </ul>

*Adapted from Bartholomew et al. (2016)*



### ***3.5.1 Step 1: Needs assessment***

Implementing this step depends on several tasks that need to be completed by the person/s planning the intervention. During the first step when completing these tasks, Oude Hengel et al. (2014) explains that the program planner is expected to 1) Plan needs assessment, 2) Assess physical environment behavioural determinants and organisational factors and 3) establish program objectives. In this step, the program planner is responsible for conducting a needs assessment to give insight into the underlying factors that cause or contribute to the problem.

The researcher did this needs assessment through phase 1 of the study. A systematic review was conducted to identify and explore best practice interventions used with children affected by HIV for community-based care and support. To identify environmental and organisational factors, the researcher interviewed various organisations to identify and describe the intervention models used by the organisations working with children affected by HIV and AIDS. Furthermore, interviews were conducted with social workers to explore their experiences of using interventions with children affected by HIV and AIDS. All these data collection methods were done to ensure that the problem is identified using these multiple sources of information. Therefore, IM is not uncommon to incorporate multiple information sources, combining different disciplinary approaches and the target group's perspectives (O'Connor et al., 2020).

### ***3.5.2 Step 2: Program outcomes and objectives***

This step is about developing a logic model of the factors that cause or influence the problem that will be the focus of the intervention. It indicates what change is needed to prevent, reduce or manage the problems identified and depicts the proposed mechanisms for change (Bartholomew Eldredge, et al., 2016). It is also important at this stage to identify who and what

will change because of the intervention. The critical tasks that must be completed during this stage involve specifying determinants and performance objectives. Performance objectives constitute the specific, measurable objectives of the intervention program that are required from the target group (Oude Hengel, et al., 2014). This means that the objectives that the researcher develops need to be simple, as this will ensure that the outcome of the intervention is achievable.

The program objectives were formulated based on the needs assessment done in stage 1. The focus of this stage was to decide on the expected outcomes of the guidelines by deciding on what the proposed guidelines should achieve in terms of interventions for children affected by HIV and AIDS. This was accomplished by summarising the findings of the data collected during the needs assessment phase. The needs assessment results showed some similarities in the data obtained from the systematic review and mostly between the results from both the organisation and social work interviews. There were also differences in the findings, and these were also documented. A summary of the findings was compiled into guidelines, and a Delphi workshop was held with the relevant experts, where consensus was reached on the draft guidelines that would form part of the program plan and design.

### ***3.5.3 Step 3: Develop program plan and design***

According to Bartholomew et al. (2006), this step involves reviewing the program ideas with stakeholders, identifying theoretical methods, choosing program methods and selecting or designing strategies. The researcher consults with intended participants and implementers, creates program scope and sequence and material list, develops documents and protocol, and reviews available material. During this stage, it is important to listen carefully to practical

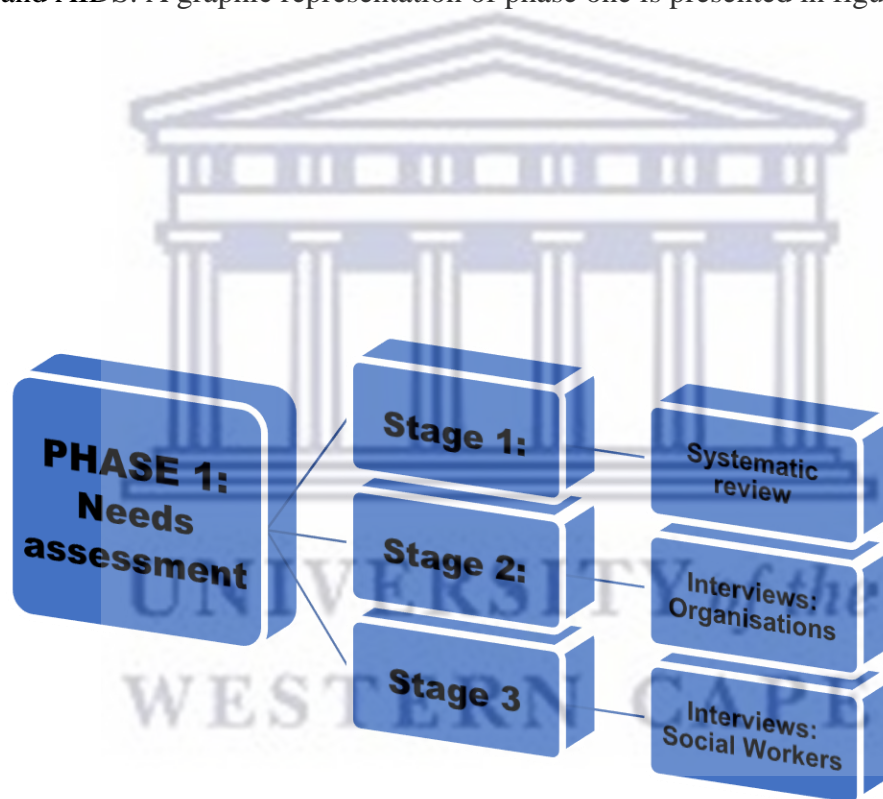
program ideas from the relevant stakeholders who may implement the intervention or participate in it (Bartholomew Eldredge, et al., 2016).

During this stage of the intervention design process, a team of stakeholders consisting of nine members with expertise in social work, child and youth care, psychology, health promotion, community work, and occupational therapy participated in the designing of the initial intervention guidelines and implementation plan for interventions aimed at children affected by HIV and AIDS. The program ideas, which consisted of guidelines drafted during stage 2, were presented to the team for discussion. Appropriate theoretical methods were identified from the literature and linked to the guidelines being developed. Decisions regarding suitable theoretical frameworks were made based on feedback from the experts at this stage. The theoretical framework that was deemed appropriate for this study is the Ecological Systems Framework. A discussion was also held about the appropriate methods and strategies most likely to work during implementation. Ultimately, the stakeholders reached a consensus about the methods and strategies deemed suitable for interventions aimed at children affected by HIV and AIDS.

### **3.6 IMPLEMENTATION OF THE CURRENT STUDY**

The study was conducted in two phases, with different stages in each phase. The first phase focused on needs assessment, and the second phase on developing guidelines for social work intervention with children affected by HIV and AIDS. Each of the two phases had different samples based on the objective of each stage. The following section will describe the methodology used in the stages of each phase. This includes an explanation of the sampling, data collection and data analysis of each stage. The study population and sampling techniques used in the various stages of the research are presented in the following section.

The first phase of this study was a needs assessment that consisted of three stages aimed at implementing objectives 1, 2 and 3. Stage 1 focused on objective 1 to identify and explore best practice interventions used with children affected by HIV for community-based care and support in Africa through a systematic review. Stage 2 was interviews conducted with various organisations to identify and describe the intervention models used by the organisations working with children affected by HIV and AIDS. Stage 3 comprised interviews conducted with social workers to explore their experiences of using interventions with children affected by HIV and AIDS. A graphic representation of phase one is presented in figure 3.1 below:



**Figure 3. 1 Phase 1 of the research process**

### **3.7 PHASE 1: NEEDS ASSESSMENT**

#### ***3.7.1 Stage 1: Systematic Review***

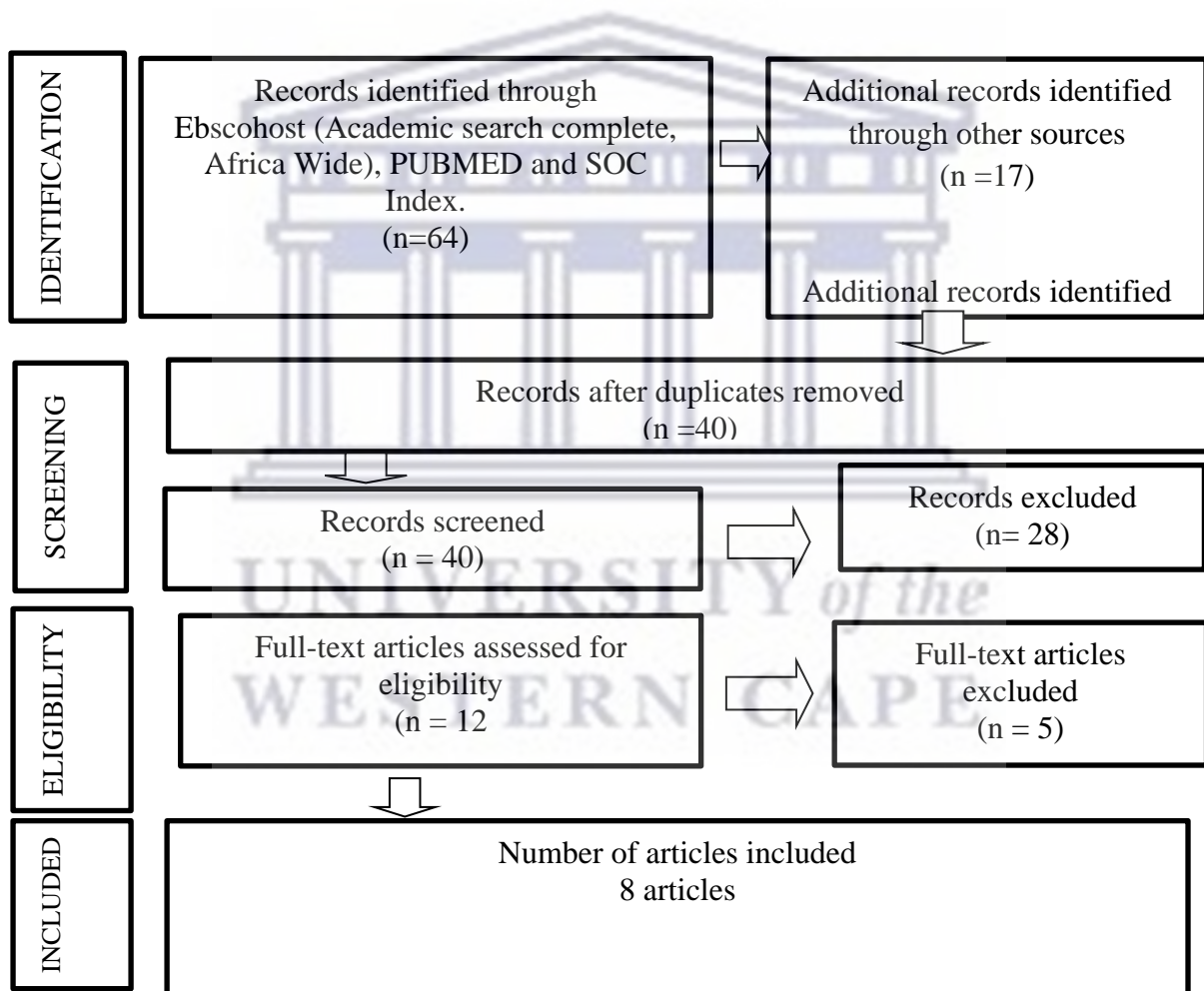
In Stage 1, a systematic review of studies on interventions for children affected by HIV and AIDS was conducted, focusing on studies done in African countries. A systematic review is an appraisal and synthesis of primary research papers using a rigorous and clearly documented methodology in the search strategy and selection of studies (Higgins & Green, 2008). A systematic review uses explicit, systematic methods to minimise bias, thus providing more reliable findings from which conclusions can be drawn and decisions made (Higgins & Green, 2008). The current study's systematic review aimed to determine best practice models of interventions used with children affected by HIV for community-based care and support in African countries. The systematic review was done as part of the problem identification process by conducting a needs assessment and social and behavioural analysis of the problem. The systematic review aimed to assist the researcher in conducting the needs assessment and understanding the research problem better before moving to the next research stage.

##### ***3.7.1.1 Search strategy***

The search strategy focused on a comprehensive search for studies in Africa published for 14 years and was conducted from January 2006 to December 2020. The search was limited to studies conducted in the African continent, full text, and peer-reviewed articles, using databases such as Ebscohost (Academic search complete, Africa Wide), PUBMED and Science Direct. The initial search period of the systematic review was a 10-year period, but with time, the researcher had to update the systematic review, which meant that more years were added to the review, thereby increasing the search period to 14 years. The initial search in the databases resulted in 64 articles identified through the databases and an additional 17 through other



searches like reference lists. After duplicates were removed, there were 40 articles left, and 28 were excluded using the ‘PICO’ method discussed in the next paragraph. Some reasons for the exclusion were studies not being relevant, no interventions mentioned, and methodology not explained. A total of 12 full-text articles from the relevant studies were put through a process of methodological quality appraisal where and the final eight articles were then chosen for inclusion in the systematic review. A flowchart of the screening process is presented in Figure 3.2 below.



**Figure 3. 2 Screening process for articles included in review**

(Adapted from Moher, Lberati, Tetzlaff and The PRISMA Group, 2009)

### *3.7.1.2 Study selection*

In the **study selection**, relevant articles were chosen by screening the abstracts for eligibility using the PICO method. Moyer (2008) describes the PICO method as identifying in the abstracts of the articles the “**P**”, which stands for the patient or problem, “**I**” for the intervention of interest, “**C**” for comparison and “**O**” for the outcome. This method allows the researcher to assess whether the article contains the required information for the SR. It also makes it easy to screen abstracts and decide whether the article is worthy of inclusion in the SR. After the initial screening of the articles, a total of seven articles were deemed eligible for inclusion. Another article was added from grey literature, resulting in a total of eight articles that underwent an appraisal process.

### *3.7.1.3 Methodological Appraisal*

Once the articles were screened, the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework was used as a methodological appraisal tool. The RE-AIM framework is an evaluation tool developed by Glasgow et al. (1999) to evaluate public health intervention programs. The framework assesses the extent to which the intervention can **R**each the target population, be **E**ffective by achieving its intended outcomes and the unanticipated negative effects, be **A**dopted by the target institutions, **I**mplement intended objectives and **M**aintain the effectiveness in recipients over time. This framework is identified as a useful tool for evaluating the impact of programs in community settings (Shaw et al., 2019). Failure to adequately evaluate programs may lead to a waste of resources and failure to improve public health (Glasgow, Vogt, & Boles, 1999). Using the RE-AIM framework as an evaluation tool assists practitioners in identifying gaps in practice and plan meaningful interventions for the future.

#### *3.7.1.4 Data synthesis and analysis*

The RE-AIM framework was used as a methodological evaluation tool to appraise the articles chosen for the SR. The framework was adapted using a set of questions that measured whether each intervention mentioned in the articles achieved any of the five RE-AIM dimensions. Twelve articles reporting on the studies of interventions were assessed using 12 questions relating to RE-AIM, and each question was allocated one point, making the total score 12 points. Only articles that scored 10 points and above were included in the review. This resulted in only eight articles being included in the systematic review as they scored above 10 points.

A data extraction tool was developed to extract relevant data such as the article details, which are author and title, demographics, country, description of the interventions and the findings of the studies. This information was used to describe, in a narrative form, the different types of interventions used by different organisations working with children affected by HIV and AIDS and to identify best practice models and gaps in the interventions. The primary researcher and research supervisors performed all levels of the review. The systematic review process was reviewed by two research supervisors who independently ensured the process's consistency and reliability at all the SR levels. Both supervisors confirmed the accuracy of the process and identified points for rectification where needed. This was to ensure that the process of the systematic review was reliable. A detailed explanation of the results of the SR is provided in chapter four of the thesis.

#### ***3.7.2 Stage 2: Interviews with organisations***

In Stage 2, a variety of organisations working with children affected by HIV and AIDS were identified through a process of purposive sampling technique. De Vos et al. (2011) describe purposive sampling as composed of elements which contain the most characteristic,

representative or typical attributes of the population. In purposive sampling, a particular case is chosen because it illustrates a particular feature or process that interests a particular study (Fouché, Strydom and Roestenburg, 2021). This means that the sample is based on the researcher's judgment, and the researcher has specific criteria for selecting the participants. The selection criteria for stage 2 of the study were as follows: 1) organisation to be implementing HIV and AIDS-related psychosocial programs; 2) Organisation could be Non-Governmental Organisations (NGO), Community Based or Church based Organisations (CBO), Non-Profit Organisation (NPO) or government department; 3) interventions or programs to be aimed at children affected by HIV and AIDS; 4) organisations to have a designated person/s able to explain about the programs. The sample comprised NGOs, CBO, NPO and other organisations working with the Department of Health (HIV/AIDS/TB/STI Directorate). The organisations were contacted telephonically, the aim of the study was explained, and questions were asked about the type of services they provided. In those organisations that met the selection criteria, a contact person's name was requested, and they were invited to participate in the workshop via the telephone, followed up by email.

#### *3.7.2.1 Data collection procedure*

The workshop aimed at identifying and describing the intervention models used by various organisations working with children affected by HIV and AIDS and sharing the results of the systematic review. The response rate to the workshop was very low, so the workshop was postponed three times. Despite the postponements, participants of the workshop could not agree on a mutual day or time to meet due to work commitments and different work schedules. Due to the problems identified by the participants, the workshop did not materialise despite numerous attempts by the researcher to postpone to accommodate all participants. Ultimately,

the researcher decided to conduct interviews in the individual organisations by setting up interviews and focus groups with all relevant role players in these organisations as this became the most practical method of data collection. In contrast to numerous methods of interviewing individuals, time constraints may necessitate data collection in a group setting (Geyer, 2021).

#### *3.7.2.2 Data collection method*

The data collection method depended on the number of people available for the study in an organisation. Focus groups were done in organisations where more than three people were available. Participants who took part in focus group interviews occupied different roles within the organisations, allowing for diverse data from the participants in relation to the different elements of each intervention. A total of seven organisations were identified as part of stage 2 of data collection. The final sample comprised eleven participants who were responsible for either managing or coordinating interventions for children affected by HIV and AIDS in their organisations. The job titles differed according to the structure of the organisation. The participants' job titles were director, manager, professional nurse, program coordinator, HIV/AIDS/STI/TB (HAST) counsellor, HAST coordinator and Child and Youth Care Worker (CYCW). The interviews started with a presentation of the findings of the SR by the researcher to the participants. The questions prepared for the workshop were used as an interview guide (*Appendix 4*). The questions of the interviews asked participants to describe the interventions, the role of the social worker, and the strengths and weaknesses of the interventions.

#### *3.7.2.3 Data analysis*

Thematic analysis was utilised to analyse the data gathered in stage 2. Thematic analysis is described by Carey (2012) as a process where the researcher looks for emerging themes, relationships and dynamics that appear from our findings and data. It requires the researcher to



be able to “systematically work through qualitative data to identify common threads of meaning, to group these into categories of meaning and to then cluster these into higher-order themes” (Willig, 2013:58). Mills et al. (2010) describe thematic analysis as a tactic for reducing and managing large volumes of data without losing the context. The researcher transcribed the information gathered from the interviews by listening to the audio recording to capture exactly what was said and how the participants said it. The next step was data familiarisation, described by Schurink et al. (2021) as where the researcher reads the text, plays and replays audio recordings or re-examines non-textual data to become intimately familiar with the content arranged into themes to make sense of the experiences of the social workers.

Central to the process of thematic analysis is a basic analytic strategy called coding. This is where one moves “from casual, observational note-taking activities and code identification to systematic coding by labelling the text.” (Schurink et al., 2021:406). Once the relevant codes were identified, the researcher could group these codes into themes. This theme development process involves identifying salient themes, recurring ideas or language, and patterns of belief that link people and settings together (Marshall & Rossman, 2006). The themes were presented in a table format that reflected the sub-themes and categories from analysing the data. The last process in the data analysis involved data interpretation which “serves as a reviewing or quality control exercise to determine if the identified themes have to be further shaped, clarified or even rejected when viewed in relation to the coded data and the research question” (Schurink et al., 2021: 408).

It became apparent that the themes that emerged in stage 2 were similar to those that came out of stage 3 of the data analysis process. This can be attributed to the fact that some of the participants of stage 2 were social workers, and some worked very closely with social workers

in the execution of interventions. Instead of presenting the findings of each stage differently, the researcher then decided to compare the findings from each stage and present these in 2 separate chapters, highlighting the similarities and differences in each chapter. Chapters five and six of the thesis give a detailed explanation of the themes that emerged in Stage 2 and 3.

### **3.7.3 Stage 3: Interviews with social workers**

In stage 3, the sample consisted of social workers working in the field of HIV and AIDS, specifically with children. Social workers in NGOs, community-based organisations and governmental institutions were sampled using a snowball sampling technique. Snowball sampling involves “approaching a single respondent or case that can provide rich data pertaining to the phenomenon being studied” (Fouche et al., 2021:383). This is done to gain information on other similar persons, and this person (single respondent) is requested to identify further people who could make up the sample. Some of the social workers used as a sample in this study stage were from the initial organisations that were part of stage 2. The researcher returned to the stage 2 organisations with social workers in their staff component and requested permission to interview them. These social workers were then asked to recommend other social workers they may have worked with in interventions for children affected by HIV and AIDS. In this way, the researcher approached the identified social workers until no new referrals were made. Most organisations rendered services to large areas of the Cape Town Metropole, and one social worker covered each area. For example, some organisations covered the Southern suburbs, Cape Flats, Milnerton and Central Cape Town, each of which comprises several townships or suburbs. A breakdown of the demographics is detailed in the results chapter. The inclusion criteria for the study were those social workers working with children under the age of 18, and these social workers must have worked in the

social work field with children affected by HIV and AIDS for a minimum period of a year. The final number of social workers were contacted telephonically and invited using email.

### *3.7.3.1 Data collection method*

The data collection method used during this stage of the study was semi-structured interviews. De Vos et al. (2011) argue that interviewing is the predominant mode of data or information collection in qualitative research. Interviews were deemed the appropriate data collection method for these stages to ensure detailed descriptions of the interventions from the participant's points of view. The choice of interviews as a data collection method was deemed appropriate for this stage, as the focus was on exploring certain aspects of the study. However, this does not mean that interviews do not come with limitations compared to other methods. The advantages of interviews, in this case, far outweighed the disadvantages. Creswell and Creswell (2018) provide a summary of comparisons. An interview schedule (*Appendix 5*) was used to interview the participants. The interviews were conducted with the social workers until data saturation was reached. The interviews were planned to be conducted with the help of research assistants in three languages: English, Afrikaans and Xhosa, which were to be recorded and transcribed verbatim. None of the participants wanted to be interviewed in Afrikaans and either chose isiXhosa or English, both languages the researcher is competent in.

### *3.7.3.2 Data collection tools*

One of the important steps in interviewing is to “determine what type of interview is practical and will net the most useful information to answer research questions” (Creswell, 2007). Focus groups were the practical type of interview to use during this stage as this method yielded the most data in these cases specifically those participants from the NGO that does the statutory intervention. Both the individual and focus group interviews were semi-structured. Researchers

generally use a semi-structured interview to gain a detailed picture of a participant's beliefs about, or perceptions or accounts of a particular topic (De Vos, Strydom, Fouche, & Delport, 2011). Semi-structured interviews were used to ensure that the participants were not limited in answering questions and could give detailed responses. De Vos et al. (2011) explain that during semi-structured interviews, the researcher has a set of pre-determined questions on an interview schedule. Still, the interview is guided by the schedule rather than dictated. In the study, the interview schedule provided guidance for both the researcher and participants but also allowed the researcher to probe for more information where participants were unclear. This, in turn, also allowed participants to tell their 'stories' without being limited only to the questions asked.

#### *3.7.3.3 Data collection procedure*

Arrangements were made for interview dates, times and venues convenient for the participants. All the participants preferred to be interviewed at their places of employment and were comfortable with being interviewed in English. A pilot study was conducted with the first two participants using the initial interview schedule, and the interviews lasted approximately 30 to 45 minutes. The responses received were unclear, and the data was not rich. Based on the responses given, an adjustment was made to the interview schedule and more probing questions were added so that the next set of participants could give detailed information. It is very useful to conduct a pilot study before attempting a major research endeavour to make the researcher aware of possible deficiencies before undertaking a fully-fledged investigation (Fouché, Strydom, & Roostenburg, 2021). The purpose of a pilot study is to assess the feasibility of the research and the data collection methods so that necessary changes can be made before engaging in the bigger research project.

A total of seven social workers participated in the initial stage of the study, and the information gathered was not enough to reach data saturation. It became clear that all the social workers working in NGOs had limited power in dealing with matters related to statutory intervention for children, as government social workers mandate statutory intervention. Most social workers working in NGOs working with vulnerable children and providing interventions for children affected by HIV and AIDS do not have the mandate to provide statutory intervention. They must refer cases to government social workers for statutory intervention. A government department responsible for statutory intervention in matters related to children in the Western Cape was contacted and invited to take part in the study. Still, the department declined the request, citing service delivery pressure and operational constraints. This has limited the study's representativeness and generalisability as the government sector is not represented in the sample. One of the few NGOs mandated with statutory intervention in cases related to children across the Cape Town Metropole was contacted through snowball sampling. They agreed for their social workers to participate in the study. Ultimately, an additional eight social workers from this NGO participated in the study, which brought the total number of participants in stage three to 15. The demographic details of the social workers are outlined in Table 3.2.

**Table 3. 2 Demographic Details of the social workers**

Participant no	Age	Gender	Home Language	Number of years qualified as a social worker	Number of years working in current organisation	Number of years working with OVC & CABHA
1	44	F	Xhosa	19	9	15
2	39	F	Xhosa	2	1	1
3	47	F	English	24	2	15



4	49	F	Xhosa	12	2	5
5	31	F	Xhosa	7	1	1
6	51	F	Afrikaans	29	5	18
8	49	F	English	24	7	7
7	46	F	Afrikaans	5	1	1
7	25	F	Afrikaans	2	1	1
7	39	F	Afrikaans	12	1	12
7	45	F	English	1yr11monts	1yr11months	1
7	25	F	Afrikaans	2 ½ y	1 ½ yrs.	1
7	37	F	Afrikaans	12	3	1
7	59	M	English	32	6	1
7	36	F	Afrikaans	10	9	4

Only one male among all the social workers participated in the study. The participants' home languages were Afrikaans, English and isiXhosa; most of the interviews were conducted in English except for one participant who expressed herself in both isiXhosa and English. The researcher accommodated this participant since she is fluent in both languages. The age range of the participants was wide, with the youngest being 25 years old and the oldest 59 years old. Two of the participants were under the age of 30 years and had less than three years of experience in social work. Five participants were between the ages of 30 and 40 years and had work experience of 7 to 12 years in social work, except for one participant who had two years of social work experience. There were six participants aged 40-50 years with experience of up to 24 years in social work, but two had less than six years' experience. The last two participants fell in the age range of above 50 years, and their work experience in social work was 29 and 32 years. All the participants had less than 10 years of working in their current organisation. Not all participants worked directly or actively with children affected by HIV and AIDS. Five

participants worked with Orphaned and Vulnerable Children (OVC), and their interventions included HIV-affected children. All these participants were from one organisation focused on child protection.

#### *3.7.3.4 Data analysis*

The data from the interviews were recorded, transcribed and analysed through thematic analysis. Creswell and Creswell (2018:193) urge researchers to “look at qualitative data analysis as a process that requires sequential steps to be followed, from the specific to the general and involves multiple layers of data analysis”, involving five steps of data analysis. These steps involve 1) organising and preparing data for analysis; 2) reading through all the data to get a sense of all the information; 3) coding; 4) summaries of the common elements; 5) checking for interrelating themes. The first step involved going through the transcripts, giving pseudonyms and linking them to fieldnotes. The second step involved reading through the transcripts to check if participants answered all the questions and to get a sense of the responses. Some of the initial responses from the initial stage were jotted down per question across all participants. For example, certain words and phrases used by participants to answer the first question were all noted against each participant. This process was followed for all the responses to the remaining questions. This resulted in a list of words and phrases for each question, making it easy to view all responses against each question. The third step was coding, where the information written down in the previous step was compared to check for similarities in the participants’ responses. This was done by organising the information in a table to write down all the keywords and information. Keywords were used to summarise the main points made by participants where common elements were found in their responses to each question. The differences in responses were also noted down to compare with the literature. The fourth step

involved making summaries of the common elements identified to generate a description of the words described in the third step. The last step involved checking the interrelating themes to see if some of the themes identified could be merged or separated further and deciding which parts become sub-themes or categories.

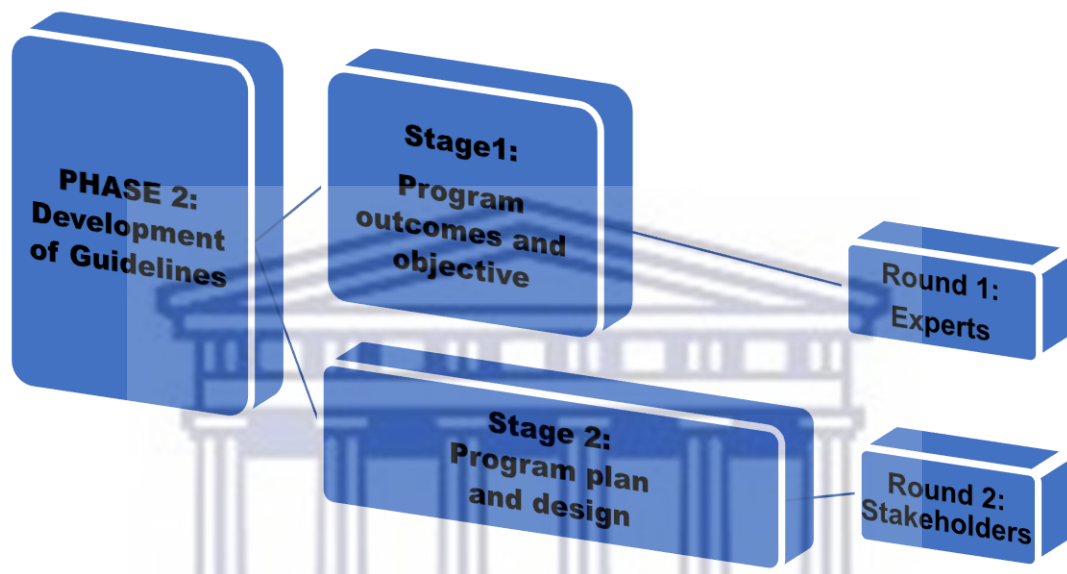
### **3.8 PHASE 2: DEVELOPMENT OF GUIDELINES**

The second phase aims to achieve objective four, which is to develop guidelines for social work intervention with children affected by HIV and AIDS. This phase of the study focused on the second and third steps of the IM process, according to Bartholomew et al. (2016), stating program outcomes and objectives and developing a program plan and design. The development of guidelines requires a thorough understanding of the process involved. This involves understanding the guidelines, purpose, and implementation plan. Guidelines are very often used in healthcare settings. They are described as “statements that include recommendations intended to optimise healthcare, whether at the clinical, public health or health policy levels” (Morgan et al., 2018: 1). Even though this definition refers to healthcare, it can be concluded that guidelines are there to guide any organisation to ensure effective and standardised service delivery. Florez et al. (2018) explain that guidelines are usually developed in various organisations, including professional and scientific associations, academic institutions and governmental organisations. Guidelines are, therefore, most likely to be specific to the scope of practice they are intended for. Furthermore, when guidelines are newly developed, efforts are needed to promote awareness, acceptance, adoption, and adherence to guidelines (Gagliardi et al., 2015). This is the reason that the Delphi method was used in the current study to seek consensus, acceptance and adoption of the guidelines from relevant experts and stakeholders. Various scholars (Florez et al., 2018; Kowalski et al., 2018; Morgan et al., 2018) argue that

guidelines should contain evidence-based recommendations to inform decision-making among practitioners, consumers and other stakeholders. Phase 2 was done in 2 stages which focused on conducting workshops using a Delphi method.

The Delphi method is an ‘interactive process to collect and distil experts’ judgments using a series of data collection and analysis techniques interspersed with feedback’ (Willis, Inman & Valenti: 2010:205). Okoli and Pawlowski (2004: 16) explain that Delphi may be characterized as a “method for structuring a group communication process so that the process is effective in allowing a group of individuals, as a whole, to deal with a complex problem”. The Delphi method is based on a series of ‘rounds’, where a set of experts are asked their opinions on a particular issue (Barret & Heale, 2020). Participants are usually experts or individuals with experience or other characteristics that qualify them for the study. In each round, panel members are asked to review the outcome of the previous round and either agree with that outcome or recommend changes along with their rationale for making those changes (Avella, 2016). The purpose of the Delphi study is to get the group of experts to come to a consensus on a set of questions or issues. The Delphi method is usually conducted through two stages (rounds) of data collection. The questions for each round are based on part of the findings of the previous one, allowing the study to evolve in response to earlier findings (Barret & Heale, 2020). In each round, panel members are asked to review the outcome of the previous round and either agree with that outcome or recommend changes along with their rationale for making those changes (Avella, 2016). Keeney et al. (2011) explain that the Delphi method has evolved into several modifications since its inception since there are no universally agreed guidelines on the use of the Delphi. This means that the Delphi method is usually adapted to fit the context where it is implemented. The current study used a modified Delphi method. Phase 2 was

conducted in two stages. The first stage focuses on conducting a Delphi workshop with experts, and the second stage is a workshop with stakeholders working with children and families affected by HIV and AIDS. A graphic representation of the research process in phase 2 is provided in figure 3.3.



**Figure 3. 3 Phase 2 of the research process**

It is important to note that the Delphi method is not always used the same way in research. Okoli and Pawlowski (2004) point out that researchers have developed variations of the method since its introduction, which are tailored to specific problem types and goals. The Delphi has evolved into several modifications since its inception. The reason for these adaptations is that there are no formal or universally agreed guidelines on using the Delphi (Keeney et al., 2011). Nha Hong et al. (2019) use the term ‘e-Delphi’ to describe a modified Delphi method where a Delphi is administered via an online web survey. A modified Delphi method was used for the current study to suit the research setting and, most importantly, given COVID-19 regulations that were applicable at the time of the study, but the tool used was not a survey but an online



workshop. A modified Delphi is described as “the process whereby the initial alternatives in response to the researcher’s questions are carefully selected before being provided to the panel” (Avella, 2016: 31). The following section will discuss the two stages of the Delphi workshop.

### **3.8.1 Stage 1: Delphi workshop with experts**

#### ***3.8.1.1 Participants***

Participants of stage 1 of the Delphi workshop were several experts who specialise in the field of caring for children affected by HIV and AIDS. The workshop was initially planned to be held as a face-to-face contact at a venue organised by the researcher. Correspondence was sent via email to the initial participants of stages 1 & 2 of the phase, inviting them to a Delphi workshop, with reminders being sent every week. There was, unfortunately, a very low response rate from the invitees, which resulted in the researcher using the snowball sampling technique. As Rubin & Babbie (2017) mention, this technique is often used when members of a special population are difficult to locate. A snowball sampling technique was, therefore, used to select the participants, where participants of phase 1 of the study were invited again via email, and those that responded were asked to invite other people who may be interested in this area of research.

#### ***3.8.1.2 Data Collection***

After the final confirmation of attendance from the participants, twelve participants ended up attending the first stage of the Delphi workshop. Participants were all academics from the University of the Western Cape with diverse areas of expertise and experience in health, child and youth care, family interventions, community work and research. Face-to-face contact was not possible due to the global pandemic COVID-19, which had brought South Africa to a national state of disaster, published in Government Gazette no 43107 on 18 March 2020. This

resulted in the country being put at different levels of lockdown, which had restrictions on movement and gatherings. Although gatherings were permitted at the time of the Delphi workshop, there were still very strict restrictions that people had to observe. Different institutions had established their protocols for allowing people entry into their venues, including proof of vaccination for COVID-19 in some. The South African government was constantly updating the COVID-19 regulations, and the researcher could not guarantee that the participants would follow these regulations. The researcher thus decided to conduct the workshop online, using platforms like Zoom and Google meet. Online Delphi workshops are not an uncommon practice. As Willis et al. (2010) also pointed out, Delphi studies are often conducted via e-mail. A decade later, there are even more advanced online platforms like Zoom, Microsoft Teams and Google meet where people can have virtual meetings.

The first Delphi workshop represented a pilot study to prepare for the second Delphi workshop. Fouché et al. (2021:236) describe a pilot study as “a way of testing and validating an instrument, before implementing the main study, by administering it to a small group of participants from the intended test population”. A pilot study allows the researcher to assess how long the study will take and identify potential concerns (Creswell & Creswell, 2018). The Delphi study was piloted first amongst the experts to test whether the guidelines made sense and to make corrections in the guidelines suggested by the participants for presentation in stage 2.

### ***3.8.1.3 Data analysis***

The researcher analysed the findings of phase one and put them in a table format to identify common themes to be presented as ‘draft’ guidelines to the experts. These are guidelines for social work intervention with children affected by HIV and AIDS. During the first round of the

Delphi study, the participants were presented with the ‘draft’ guidelines via an online workshop. This is usually the first step in a Delphi study which often involves “a presentation of a questionnaire to a panel of ‘informed individuals’ in a specific field of application, to seek their opinion or judgement on a particular issue” (Keeney et al., 2011: 6). In the case of the current study, there was no questionnaire, but a series of questions were posed to the participants in relation to the guidelines and input was asked from the participants regarding the flow, clarity and feasibility of the guidelines. At the end of round one, participants reached a consensus and gave recommendations on how the guidelines should be. Once the first Delphi workshop was concluded, corrections were made based on the consensus reached by the participants and the guidelines were updated for a final presentation to the stakeholders. The researcher was able to make changes as suggested by the experts, and these were presented in round two of the Delphi.

### **3.8.2 Stage 2: Delphi workshop with stakeholders**

#### **3.8.2.1 Participants**

An invitation to the participants of stage 2 was sent via email to several stakeholders working with children and families affected by HIV and AIDS. Participants were recruited via email. The initial sampling technique for selecting the experts for this stage was purposive sampling. The sample selection criteria were as follows: a minimum of 5 years working in the field of HIV and AIDS, direct involvement in the planning and implementation of interventions for children affected by HIV and AIDS as well registration with a professional body of the specific profession where appropriate. The participants were recruited through snowball sampling, where they were asked to forward the invitation to other stakeholders they regarded as relevant and those providing interventions relating to OVCs and children affected by HIV. Even though

the invitation was extended to paraprofessionals such as child and youth care workers and auxiliary social workers, there was no response from any of these paraprofessionals. The participants in the workshop were experts from the disciplines of social work, psychology, physiotherapy and academics working with children in the field of HIV and AIDS.

### ***3.8.2.2 Data collection***

In collecting the data for stage 2 of the Delphi workshop, the researcher followed the guidelines for conducting Delphi studies given by Okoli and Pawlowski (2004). The experts were put together in a group where a series of questions were posed in relation to a research problem. The researcher facilitated a discussion/group communication of the questions following a systematic process and summarized the responses once the participants reached a consensus. The systematic process of group communication, according to Okoli and Pawlowski (2004), can be achieved through the feedback of individual contributions of information and knowledge from the experts, assessment of the group judgment or view, the opportunity for individuals to revise views and some degree of anonymity for the individual responses.

The second round of the Delphi workshop followed the same process as stage one. The participants were presented with the summary of the adapted guidelines based on the recommendations from stage one. The participants were also asked to give their input on the guidelines' flow, clarity and feasibility. Further recommendations were made in stage two by the participants about the guidelines. After extensive discussions amongst participants and differing opinions, a consensus was eventually reached on the most appropriate aspects to be included in the guidelines and how the guidelines should flow.

### **3.8.2.3 Data analysis**

Thematic data analysis was used to analyse the themes that came out. These recommendations that the stakeholders gave were summarised and put together in relation to existing literature relating to the themes identified. These themes comprise the final guidelines for social work intervention with children affected by HIV and AIDS. A detailed explanation of the guidelines is presented in chapter 7.

## **3.9 ETHICAL CONSIDERATIONS**

Permission to conduct the study was requested from the University of the Western Cape's Humanities and Social Sciences Research Ethics Committee and was granted (*Appendix 1*). Participation in the study was purely voluntary. All participants were provided with an information sheet which explained what the study entails, the aim and objectives of the study and their role as participants (*Appendix 2*).

*Informed consent* was obtained through a consent form provided to all the participants and explained in detail by the researcher (*Appendix 3*). Part of the explanation on the consent form highlighted the right of the participants to refuse participation as well as their right to withdraw participation anytime they wanted to. Permission to record interviews was also obtained from the participants as explained in the consent forms and all participants agreed to be audio-taped.

*Confidentiality* – The researcher maintained the right to confidentiality and anonymity of participants. All information shared by participants was not shared with anybody else and was used solely for research purposes. Information on the consent form and any other tools containing the participants' personal information was kept confidential and saved in password-protected files on the researchers' computer. As part of the consent form, each member who



participated in group discussions must sign a confidentiality clause to ensure that all information discussed in the groups remains confidential and is not shared outside the groups. During the reporting of the findings, the identity of the participants was protected by using pseudo names such as 'participant 1' in the process of transcribing the interviews and in the research report.

*Non-Maleficence* - Researchers need to ensure that the research does not cause any harm to participants and that preventative measures are put in place for unforeseen cases where participants may be harmed as a result of the study. Participation in the study did not present any immediate threat or harm to the participants. If any participants felt traumatised or suffered any emotional distress arising from the group discussions or interviews, they were informed that they would be referred for counselling to a relevant and appropriate resource. Before the interviews were conducted, the researcher sought information on counselling services available for the different organisations and made arrangements, accordingly, should the need arise. During the study, no participants reported feeling traumatised or needing counselling after the interviews.

*Beneficence* - Participants were informed that there was no compensation offered in cash or kind to any participants. However, it is also important to note that even though there was no compensation offered for participating in the study, the study's results benefit the participants in improving or at least providing guidelines for their interventions. The study's results will be made available to the organisations that participated in the study and the organisations that employ the social workers involved in the study. In this way, the results do not benefit individuals but organisations at large.

### 3.10 REFLEXIVITY

It is important to acknowledge that the researcher influences and shapes the research process. Willig (2013) argues that the researcher influences the research process both as a person (*personal reflexivity*) and as a theorist/thinker (*epistemological reflexivity*). Reflexivity allows the researcher to reflect on how the researcher might influence the research and its findings. As a researcher, I found ways to make sure that I reflect on my role in the research and how this has affected the research process. In reflexivity, the researcher needs to apply 'vigilance of self', which Carey (2012:20) describes as a way by which one's assumptions are recognised as potential sources of bias. In the study, the researcher made use of the suggestion by Willig (2013) that reflexive considerations are discussed under a separate heading at the end of a research report, whereby the researcher reflects on how the research has changed him or her and their way of thinking about the subject matter of the research.

This section reflects on the researcher's feelings, values and biases and how these were present and dealt with during the research process. Willig (2013) further argues that the researcher needs to say something about their relationship with the research, their expectations of it and their investment in what may be discovered because of it. In this case, the researcher has developed an interest in the topic based on their experience of working in the field of HIV and AIDS with children who are both infected and affected as well as having taught the subject matter. The researcher did not have a problem separating her personal experience working in the field and the participants' responses. This is probably because, in the past, the researcher was not involved in implementing interventions in her professional capacity but was more involved in facilitating set training programs for the department of health in the Western Cape. The researcher's expectation was that government social workers would be involved in the

study since the government funds social work, and interventions must follow government regulations. It was quite disappointing when the request for the study was declined by the government department when their social workers are the ones dealing with most cases that require statutory social work intervention. The researcher expects that the findings of this research will provide new information and insight into interventions used by social workers with children affected by HIV and AIDS, which could help with program planning and evaluation.

### **3.11 TRUSTWORTHINESS**

The researcher needs to verify data within qualitative research to ensure that the data is trustworthy. Guba's model, according to De Vos (2005), identifies four elements of trustworthiness that qualitative researchers should consider in pursuing a trustworthy research project: truth value, applicability, consistency and neutrality. Truth value is the degree to which the researcher has established confidence in the truth of the research findings for the subjects and the context in which the research was undertaken (De Vos et al., 2001: 331). The truth value of the findings of the current study will be discussed in relation to the four constructs: credibility, transferability, dependability and conformability.

*Credibility* of the findings aims to show that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified. The researcher ensured credibility by describing how the population and sample were identified. A detailed account of the participants in each stage is given. The sampling technique used to select the participants and the selection criteria for each stage has also been explained in detail. Any changes in the methodology, e.g., sampling techniques, are also reported and justified.

*Transferability* of the research findings is the extent to which the findings of one study can be applied to other situations. This also refers to the degree to which the findings can be applied to other contexts and settings. Transferability also ensures that the researcher can reflect on the study's generalisability. Designing a study with multiple cases, multiple informants, or more than one data-gathering method can greatly strengthen the study's usefulness in other settings (De Vos, Strydom, Fouche, & Delpont, 2011). To ensure the transferability of the case of the study, the researcher used more than one data-gathering method and multiple informants to gather the data. The data gathering methods are systematic review, interviews and a Delphi study. Even the interviews allowed the researcher to use multiple informants as individuals or groups. It is important to note that even though multiple informants were used, the stage 3 data is only limited to the NGO sector and may not be generalised or applicable to the government sector as this sector was not represented in the sample.

*Dependability* refers to the issue that the result will be the same if the work were to be done again in the same context, using the same methods and selecting the same participants. This focuses on whether the results would be consistent if the research were repeated in the same context with the same participants. De Vos et al. (2005: 346) explain that through dependability, the researcher attempts to "account for changing conditions in the phenomenon chosen for the study as well as changes in the design created by increasingly refined understanding of the setting". The researcher ensured dependability when she could adapt to the changing context of the research setting in stage 2 of the study when the participants could not come to the workshop due to work commitments. The researcher had to change the study design slightly to suit the research setting.

Furthermore, the researcher conducted interviews in the environment of the participants at a time that was convenient to them, which shows that the researcher was able to adapt to the environment of the participants and did not expect participants to adapt to the researcher's environment. This indicates that if the research can be repeated, it is more likely to yield the same results as it was done to suit the context of the participants and not that of the researcher. However, it is also worth noting that some factors beyond the researcher's control might affect research results. These are confounding variables relating to focus groups, such as participants having to answer questions in the presence of colleagues, including senior personnel. This might influence how participants answer questions, as they might not be as open as they would have been if they were alone.

Furthermore, the emergence of the global pandemic COVID-19 during the final stage of the research meant that the researcher had to adapt the Delphi study to suit the context and state of the country at the time. The data collection of this stage meant that participants had to attend a virtual Delphi workshop through online platforms like Google meet and Zoom. Both online platforms have advantages and disadvantages. The advantage is that more people could attend the workshop, and they did not have to make travel arrangements to a research venue or leave their comfort zones. On the contrary, the researcher did not have complete control of the research setting to check if participants were fully attentive during the workshop. Participants could have easily logged on to the online meeting and been busy with something else. Despite these confounding factors relating to online platforms, it can still be argued that they have a significant role in future research in ensuring dependability. If the same research can be done in the same context of online platforms, it is more likely to yield the same results.



*Confirmability* refers to the qualitative researcher's objectivity, sometimes referred to as neutrality. This is about whether another person can confirm the results of the study. Neutrality is described by De Vos et al. (2005) as the degree to which the findings are a function solely of the informants and conditions of the research and not of other biases, motivations and perspectives. The confirmability of the research findings is closely linked to dependability, as discussed above. The researcher ensured this by making sure that the research setting was adaptable. Furthermore, the researcher also ensured confirmability through reflexivity by reflecting on her feelings and potential biases in the research process.

Additionally, to ensure the trustworthiness of the data, the researcher uses a variety of methods such as member checking, thick descriptions and reflexivity (described in the previous section). Member checking is described by Creswell (2007) as when the researcher takes the final report or specific descriptions or themes back to the participants and determines whether the participants feel that they are accurate. The researcher also did an ongoing member checking with participants at each stage of the research to ensure the true value of the data. This was done by summarising the participants' responses during the interviews to ensure that the participants could confirm that the information was captured correctly. This ensured that the interpretations done by the researcher were true representations of the respondent's meanings. The researcher has also provided detailed descriptions of the findings in the research report, as recommended by De Vos et al. (2011) and Creswell and Creswell (2018), to ensure the study's validity. Creswell and Creswell (2018) argue that when the researcher uses rich, thick descriptions to convey the findings, this will ensure that the results become more realistic and richer. Trustworthiness also enables the reader to make their own judgement about the validity of the interpretation.

### 3.12 CONCLUSION

This chapter presented the research methodology used for the study. The chapter started by explaining the research approach that guided the study as well as the philosophical assumption of the study. The rest of the chapter explains the IM research design and its application to the current study, which was done in two phases with the steps involved in each phase. The activities at each stage were explained, including the study population and sampling, data collection methods and data analysis. The chapter concludes with a description of the trustworthiness and ethical considerations of the study.



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## **STRUCTURE OF THE FINDINGS CHAPTERS**

The findings of chapters 4-6 are presented in the format of journal articles and were submitted to different academic journals to be considered for publication. The details of the submissions are presented in the table below, and the content of these chapters is explained after the table. Evidence of submission to the journals is submitted as appendices. The details of the submission of articles are as follows:

<b>Chapter</b>	<b>Title</b>	<b>Journal</b>	<b>Date of submission</b>	<b>Status</b>
4	A systematic review of interventions used with children affected by HIV in Africa for community-based care and support using a RE-AIM framework.	Child and Adolescent Social Work	07/10/2022	Under review
5	A needs assessment for social work interventions for children affected by HIV and AIDS	Social Work/Maatskaplike Werk	05/08/2022	Feedback received in November 2022. Recommended submission in Jan 2023
6	Implementation of interventions for children affected by HIV and AIDS in the Cape Town Metropole: perspectives from key role players	Journal of Social Aspects of HIV/AIDS	20/08/2022	Under review

## **CHAPTER 4**

# **A SYSTEMATIC REVIEW OF INTERVENTIONS USED WITH CHILDREN AFFECTED BY HIV IN AFRICA FOR COMMUNITY-BASED CARE AND SUPPORT USING A RE-AIM FRAMEWORK.**

### **ABSTRACT**

In Sub-Saharan Africa, the problem of children that are orphaned and vulnerable as a direct result of HIV is still evident. Consequently, this increases the burden on extended family members and over-stretched government resources, hence the need for reliable community-based interventions to ease this burden. This systematic review aimed to identify a best practice model to increase support for children affected by HIV and AIDS using the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework. A comprehensive search was conducted for studies published over 14 years using various databases and focusing on African studies. The articles reporting on the studies were put through a methodological quality appraisal process using the RE-AIM framework, and eight articles were included in the review. The results yielded studies conducted in Kenya, South Africa, Rwanda and Uganda, focusing on psychosocial support and empowering families of HIV-affected children. The RE-AIM framework revealed positive outcomes in most of the interventions and identified that collaborations between communities and relevant stakeholders in community-based interventions are essential for the success of interventions. Long-term follow-up and flexibility in accommodating different cultural contexts are necessary to evaluate the effectiveness of interventions.



**Keywords:** HIV and AIDS, children, intervention, community-based care, social work, support, RE-AIM

#### **4.1 INTRODUCTION**

The chapter is presented in a format of an article as it was submitted to the Journal of Child and Adolescent Social Work. The article is still under review. The chapter starts with background information about the topic, and the next section describes the material and methods used for the systematic review (SR). Results of the SR are presented using the RE-AIM framework, and the last section focuses on a discussion of the findings

#### **4.2 BACKGROUND INFORMATION**

The UNAIDS (2022) reports that the number of people living with HIV (PLWH) is estimated to be approximately 38 million. A total of 25,6 million of these PLWH are from Sub-Saharan Africa, which accounts for just over half (67,3 %) of the global population of PLWH. This indicates that the high burden of HIV infections lies in the Sub-Saharan Africa region. The number of PLWH continues to grow compared to a decade ago, which was reported by (UNAIDS, 2012) to be around 34 million. This increase could be attributed to the increased life span of people infected with HIV due to the global response to HIV and AIDS, such as the provision of Anti-Retroviral Treatment (ART). Access to ART has changed historical patterns of mortality as more HIV-positive people can live longer and continue their normal lives living with HIV (UNAIDS, 2022).

Despite the worldwide response to the prevention of HIV and management of AIDS, the challenge remains that there is no cure for AIDS to date and people still die from AIDS-related illnesses. An estimated 14.9 million children worldwide lost one or both parents due to an

AIDS-related cause in 2021, and three-quarters of these children live in sub-Saharan Africa (UNICEF, 2022). This shows that the crisis of vulnerable children due to HIV and AIDS is still an issue as the parents are most likely to die or become sick from AIDS-related illnesses, leaving their children behind to fend for themselves. As people already infected with HIV continue to die, the number of orphaned children continues to increase, placing a strain on the extended family system that traditionally provided care and support to orphaned children (Nabunya et al., 2019). Consequently, this puts pressure on extended families and pressure on government and community resources. Family structures and roles also change due to the AIDS epidemic. Children end up being cared for by extended family members when their parents cannot care for them because of deteriorating health or death due to HIV and AIDS-related illnesses. This indicates a need for intervention by social workers and other stakeholders involved in the care and support of children affected by HIV.

Previous research has shown that children affected by parental HIV present with elevated stress levels and negatively affected well-being (Breckenridge et al., 2019; Murphy et al., 2015; Tucker et al., 2016). HIV illness in parents affects their ability to fulfil their caregiving roles and results in children being left vulnerable (Breckenridge et al., 2019). A vulnerable child is described as “a child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance and which prevents the fulfilment of his or her rights” (DSD, 2005). Children left without visible means of care may miss important developmental activities such as access to food and shelter, parental guidance and school attendance. This poses a serious risk to child development and needs scaled-up interventions (Sherr et al., 2018). Li et al. (2014) highlight the importance of empowering families to confront HIV-related challenges and the need to develop child-adequate and age-specific

intervention strategies. On the other hand, Murphy et al. (2015) argue that community-based services may be ideally placed to accommodate such provision and deliver urgently needed support to these children.

A number of interventions were implemented across some African countries (Doku, 2010; Lachman et al., 2014; Sherr et al., 2018; Thurman et al., 2016) in an attempt to support children affected by HIV and AIDS (CABHA), but there is no mention of the role of the social worker. Despite many interventions being implemented, there are limited evaluations of their effectiveness and no evaluations of post-programme outcomes (Visser et al., 2015). Furthermore, there is extensive literature on the challenges faced by children affected by HIV, but disproportionately less is known about effective interventions to support CABHA (Richter et al., 2015). This raises a concern about the efficacy of interventions for CABHA and how the evaluation of such interventions is conducted, which is the motivation behind conducting this systematic review.

This study focused on conducting a systematic review of interventions implemented in the Sub-Saharan African countries since this region carries most of the HIV and AIDS burden, as reflected by the UNAIDS (2022) statistics. The aim was to identify a best practice model to increase support for CABHA by using the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework. The information provided by the review is meant to assist social workers in evaluating existing intervention programs to enhance the planning and implementation of future interventions aimed at CABHA.

## **4.3 METHODS**

### ***4.3.1 Search strategy***

A comprehensive search was conducted for studies published for a period of 14 years, starting from January 2006 to December 2020, using databases such as Ebscohost (Academic search complete), PUBMED and SOC Index. The terms used to search for articles where HIV and AIDS, affected children, intervention, HIV-affected children, community-based intervention and children affected by HIV/AIDS. The titles and abstracts of articles were screened and chosen using specific inclusion criteria, explained in the following section. The reference lists of the chosen articles were used to further search for additional articles which did not feature in the original search of the databases. These articles were retrieved, those that were not appropriate were excluded, and the relevant articles were chosen. This process continued until there were no new or relevant articles found.

### ***4.3.2 Inclusion criteria***

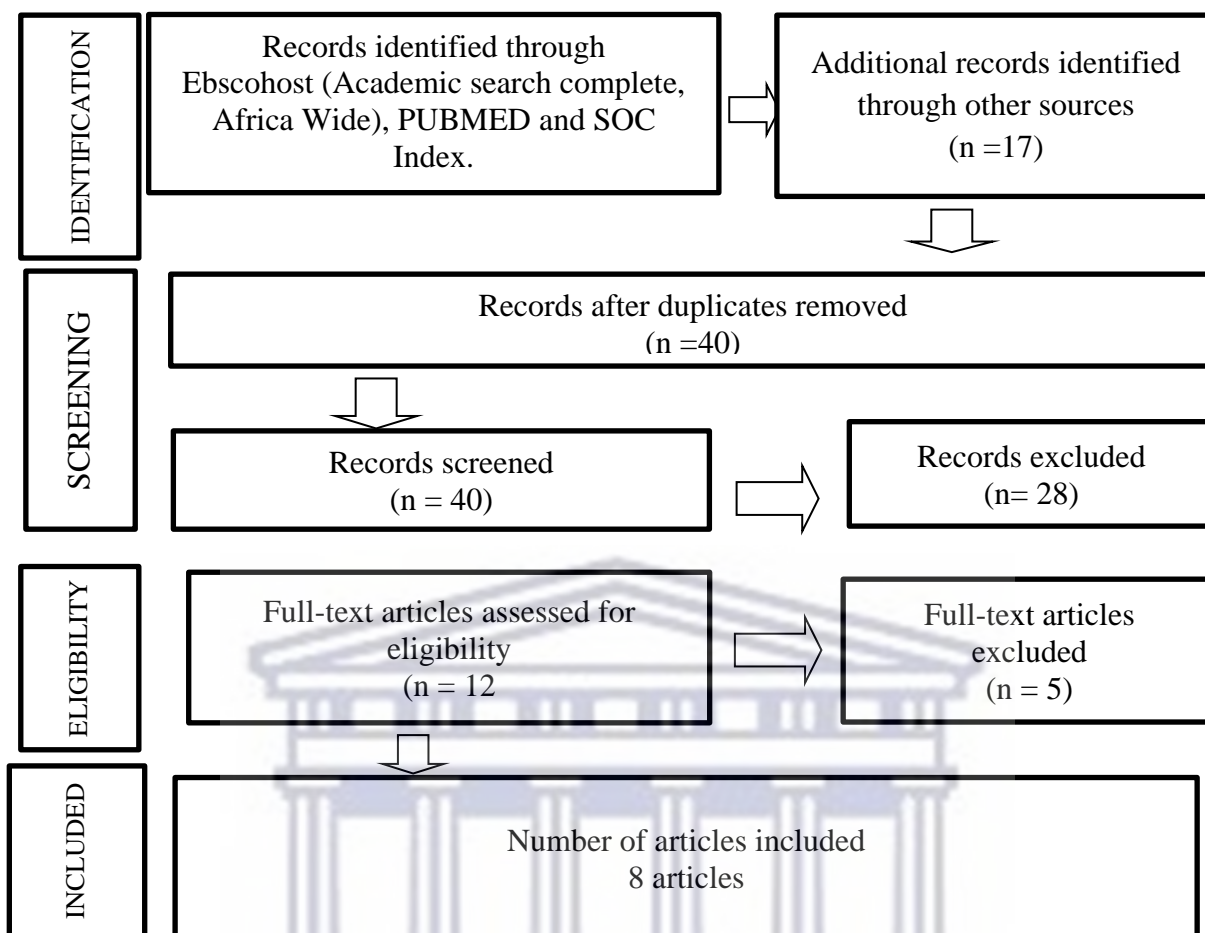
The criteria for inclusion for the articles were publications from 2006 to 2020. All publications had to be written in English. The range of publications chosen was peer-reviewed journal articles. The geographical location of the articles chosen was limited to the African continent. There were no limitations regarding the type of studies included, which were done to capture a wide range of studies and methods. The studies included were mostly those that used community, school and family-based models to evaluate the effects of interventions for children affected by HIV and AIDS. Articles that were done in countries outside Africa were excluded.

### 4.3.3 Study selection

The relevant articles were chosen by screening the abstracts for eligibility using the PICO method. Moyer (2008) (describes the PICO method as **P** for the patient or problem, **I** for the intervention of interest, **C** for comparison, and **O** for the outcome. In the abstracts reviewed, the *population* were mostly children affected by HIV and AIDS. Some chosen studies were also used in their *interventions*, with others caring for children affected by HIV and AIDS. The intervention was any intervention aimed at assisting children affected by HIV and AIDS. The element of *comparison* was not looked at as the inclusion criteria were open to all types of studies and not necessarily limited to comparative studies. The outcome was the end result of the interventions implemented.

The articles that did not meet the inclusion criteria were excluded from the review. Some reasons for exclusion were the content that was not relevant, some studies did not contain interventions conducted, and some were peer reviews. A total of 64 articles were found through the database search, but only 40 were eventually screened. A total of 12 full-text articles from the relevant studies were put through a process of methodological quality appraisal using RE-AIM. The final eight articles were then chosen for inclusion in the systematic review. The screening process was conducted by two independent reviewers monitoring the research process to ensure the credibility and consistency of the systematic review. A flowchart of the screening process is presented in Figure 4.1.





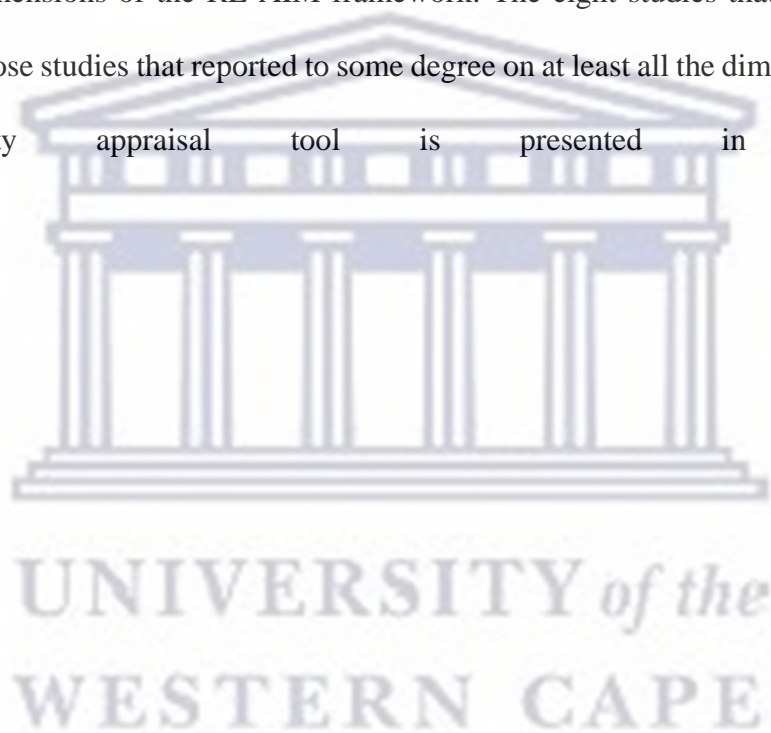
**Figure 4. 1** Screening process for articles included in the review

*(Adapted from Moher, Lberati, Tetzlaff & The PRISMA Group, 2009)*

#### **4.3.4 Data synthesis and analysis**

The methodological evaluation tool used to appraise the articles chosen is the RE-AIM Framework Adapted from (Glasgow et al., 1999), which looks at the Reach, Effectiveness, Adoption, Implementation and Maintenance of intervention studies. The framework assesses the extent to which the intervention can **R**each the target population, be **E**ffective by achieving its intended outcomes and the unanticipated negative effects, be **A**dopted by the target institutions, **I**mplement intended objectives and **M**aintain the effectiveness in recipients over time. Glasgow et al. (1999) argue that these dimensions occur at multiple levels, such as

individual, clinic or organisation and community and interact to determine the impact of the intervention. For the purposes of the review, the framework was adapted using 15 questions that measured whether each intervention achieved any of the RE-AIM dimensions. 12 articles reporting on the studies of interventions were assessed in relation to the questions, and each applicable question was awarded one mark. A zero mark was awarded in cases where the question was not applicable. All studies that scored 10 points and above were included as part of the review, and those that scored below 10 points were excluded. These studies did not report on all of the dimensions of the RE-AIM framework. The eight studies that were ultimately selected were those studies that reported to some degree on at least all the dimensions. The RE-AIM quality appraisal tool is presented in table 1.



**Table 4.1 RE-AIM Quality Appraisal Tool**

		Betancourt et.al (2014)	Bhanan et.al (2014)	Boon et.al (2009)	Goodman et.al (2014)	Han et.al (2013)	Karimli et.al (2019)	Kumakech - 2009	Mueller- 2011	Nebunya et.al (2019)	Thurman et.al (2014)	Tomlison et.al (2016)	Visser et.al (2015)
<b>DIMENSIONS</b>	<b>QUESTIONS</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>	<b>YES =1 No=0</b>
<b>REACH</b>	Does the article indicate who the program is intended for (Inclusion and exclusion criteria)	1	1	1	1	1	1	1	1	1	1	1	1
	Does the article report on the representativeness of the target population?	0	0	0	1	1	0	1	0	1	0	1	0
	Does the article report on participation rate?	1	1	1	1	1	0	1	1	0	1	1	1
<b>EFFECTIVENESS</b>	Did the program achieve the intended objectives?	1	1	1	1	1	1	1	1	0	0	1	1
	Do they report on the limitations of the intervention?	0	1	1	1	1	1	1	1	1	1	0	1
	Reports on at least one outcome of the intervention	1	1	1	1	1	1	1	1	0	0	1	1
	Reports on attrition	1	1	1	1	1	0	1	0	1	1	0	0
	Is the setting clearly described?	1	1	0	1	0	1	1	1	1	0	1	0
<b>ADOPTION</b>	Does the evaluation report on the adoption of the intervention by the participants or the organisation?	1	1	1	1	0	0	1	1	0	1	1	0
	Reports on who delivered the program	1	1	1	1	1	0	1	1	0	1	1	0

	Describes the duration and frequency of the intervention	1	1	0	1	1	1	1	1	1	0	1	0
<b>IMPLEMENTATION</b>	Has the staff / participants of the organisation/intervention been involved in delivering the program (cost implications)	1	1	1	1	0	0	1	1	1	1	1	0
	Reports on intended and delivered interventions	1	1	1	1	1	1	1	1	1	0	1	0
<b>MAINTENANCE</b>	Does the article report on the long-term effects of the intervention (after 6 months)	1	1	0	0	1	1	0	0	1	1	1	1
	Do they report on the indicators used for intervention follow-up?	1	0	0	0	0	0	0	0	0	1	0	1
	<b>TOTAL</b>	<b>13</b>	<b>13</b>	<b>10</b>	<b>13</b>	<b>11</b>	<b>8</b>	<b>13</b>	<b>11</b>	<b>9</b>	<b>9</b>	<b>12</b>	<b>7</b>



### 4.3.5 Data extraction

A data extraction tool was developed to extract relevant data from the articles. The tool was designed to extract data such as the article details, sample, country, description and aim of the interventions as well the findings of the studies. The summary of the data from the studies is outlined in Table 2.

**Table 4.2 Data Extraction Tool**

Article	Study Design	Sample	Country	Aim of the study	Description and duration of interventions	Implementation staff	Outcome	Follow up
1. Betancourt et al., (2014)	Pre-Post Design	N = 20 HIV-affected families with at least one HIV-positive caregiver and one child 7–17 years old  -Caregivers willing to discuss HIV and AIDS during intervention -Caregivers ranged from 30 to 70 years of age)	Southern Kayonza District in Rwanda	To reduce mental health problems among HIV-affected children through improved child–caregiver relationships, family communication and parenting skills, HIV psychoeducation and connections to resources.	<b>The Family Strengthening Intervention (FSI)</b> - A structured intervention with four core components delivered via six main modules focusing on:  - Building parenting skills and improving family communication; developing a family narrative to increase family connectedness and hope; providing family psychoeducation on HIV transmission and disclosure; navigation of non-formal and formal resources	Six counsellors were six with Rwandan bachelor-level psychologists. They were supervised by a program manager and an experienced clinical psychologist from the University of Rwanda	- Caregiver-reported improvements in family connectedness, good parenting, and social support.  - Children's pro-social behaviour was sustained and strengthened post-intervention to 6-month follow-up.  <b>3)</b> Improvements in child perseverance/self-esteem, depression, anxiety and irritability were seen at follow-up	Comprehensive quantitative batteries assessing main study outcomes were administered immediately before, after intervention and 6-month follow-up.



2. Bhana et al. (2014)	<b>Randomised Controlled Trial</b>	65 families = 65 preadolescents aged 10 to 13 years and their families.	South Africa: (Pietermaritzburg in KwaZulu-Natal Province)	<b>AIM:</b> to promote health and mental health among HIV-infected early adolescents	<b>The VUKA family program A new culturally tailored cartoon storyline and curriculum:</b> 10-session intervention of approximately 3 months duration. HIV-infected youth and their primary caregiver come together with other affected families for sessions, including multiple family group activities and separate parent and child group activities.	Lay counsellors supervised by a psychologist to deliver the intervention in an engaging and structured way. The curriculum was reviewed by a multi-disciplinary team (physicians, nurses, psychologists, lay counsellors, researchers and patients)	– Increased adherence in the intervention group than that reported in the comparison group. - HIV treatment knowledge scores and the frequency and comfort of communication about HIV and other sensitive topics increased - Perceptions of external stigma were reduced	All participants were assessed at two-time points, at baseline and approximately two weeks after the last intervention session.
3. Boon et al. (2009)	<b>Longitudinal one-group study.</b>	(N=202) IsiXhosa-speaking people of 60 years and older who were responsible for caring for their sick children and/or (orphaned) grandchildren due to HIV and AIDS.	South Africa (Motherwell, a township in the city of Port Elizabeth in the Eastern Cape province)	To address the psychosocial determinants of older people's perceived ability to care for sick children and vulnerable grandchildren by using suitable strategies.	<b>A Community-based Pilot Health Education Intervention:</b>  Four weekly workshop sessions, each of about 3 hours, containing a range of topics. Workshops were delivered as four modules focusing on (HIV and AIDS information, skills to bridge the generational communication gap, basic home-based nursing, and accessing social assistance)	Six community health workers and three community members were employed by Age-in-Action, a local non-governmental organisation and a partner in the project.	Participants reported:  - Increased competence in providing nursing care to their dependents. - A more positive attitude towards people living with HIV and AIDS - Increased level of HIV and AIDS knowledge	A pre-test at the start of the program, a post-test immediately after the program, and a follow-up test three months after the end of the program.
4. Goodman et al. (2014)	<b>Cross-sectional survey</b>	<b>N = 693</b> Families - Cohort 1 = 312 (319 household heads interviewed) - Cohort 2 = 185 (187 household heads interviewed) - Cohort 3 = 196 (201 household heads interviewed)	Kenya	To assess the differences in health and livelihood outcomes associated with participation in a community-based empowerment program	<b>A community-based empowerment 3-year program for orphan families</b>  -Combines three different OVC-targeted approaches: income generation, cash transfer, and empowerment - Program coordinators deliver training on business, health, hygiene, and agricultural skills at	Screening for program inclusion is conducted by community stakeholders, village chiefs, and religious leaders.  Training provided by program graduates, senior program	Statistically significant health and livelihood outcomes changes were found following participation in the intervention. This suggests the importance of social, economic and health-related	No baseline survey was done; post-intervention was done only 12 months after joining intervention

					weekly group meetings.	members, or other community leaders	protection in decreasing risks associated with OVC status.	
5. Han et al. (2013)	<b>Cluster Randomised Controlled Trial</b>	(N=297) AIDS-orphans in the past 2 years of primary school (ages 12 to 14yrs). Selected from 10 comparable primary schools	Uganda (Rakai and Masaka Districts of southwestern Uganda)	To develop and examine a family economic empowerment intervention that creates economic opportunities for low-income families caring for AIDS- orphans in Ugandan communities	<b>A Family economic empowerment and mental health program:</b> - Ten training sessions on career planning and financial management - An average of one mentorship meeting per month during the 12-month intervention period. - Counselling and mentorship, food aid and educational materials	Information on persons responsible for the implementation of the programme is not provided	- Children in the treatment group reported significantly lower scores on hopelessness and depression after the intervention.  - Both groups reported a reduction in depression levels at follow-up, with a reduction greater among the treatment group	Baseline scoring was done at the beginning of the program, and the post-test done 12 months after the intervention
6. Karimli, et al. (2019)	<b>Cluster-randomised experimental design</b>	N = 1410 school-going AIDS-orphaned children ages 10 and 16 years old in 48 primary schools	Uganda (Rakai and Masaka Districts of South Western Uganda)	To examine the effects of the Bridges intervention on children's mental health while exploring the intersections with household wealth, child work, and child poverty	<b>Bridges intervention</b> – a family-based combination intervention comprising economic empowerment and asset accumulation centred around micro-savings and financial management training and mentorship	Information on persons responsible for the implementation of the programme is not provided	Results demonstrate a significant positive effect of the intervention on children's mental health at 24 months  No evidence was found for mediating the effect of household poverty or the child's work in transmitting the effect of family-based economic empowerment intervention on children's mental health	Data were collected from children at 5-time points (baseline, 12, 24, 36 and 48 months)
7. Kumakech et al. (2009)	<b>Cluster Randomised Controlled Trial</b>	(N = 326) children aged 10–15 years, reported having lost one or both parents due to AIDS	Uganda (Mbarara Municipality situated in Mbarara District in	To provide social support in order to improve the psychosocial well-being and coping of AIDS orphans:	<b>Peer-group support intervention:</b> 16 psychosocial exercises were implemented over 10 weeks. The intervention also included periodic somatic	Implemented by trained primary school teachers under the supervision of the researcher and a	- Symptoms of anxiety, depression, and anger were lower than among the control orphans at follow-up  - The study found no significant effect of peer-	Baseline and 10-week follow-up

			southwestern Uganda)		health assessments and treatment on the psychosocial well-being of AIDS orphans	professional counsellor	group support intervention on the self-concept of the orphans.	
8. Mueller et al. (2011)	A quasi-experimental cross-sectional post-intervention survey (177 intervention groups and a control group of 120).	N=297 Children aged 8–18 years 177 attendees and a control group of 120). Children selected from an existing school-based programme based on arbitrary class timetabling	South Africa (Nekkies township near Knysna, Western Cape Province)	To reduce psychosocial problems by increasing children's self-esteem, self-efficacy and HIV insight health.	A community-based art therapy intervention MAD ('Make A Difference') about Art for children affected by HIV and AIDS. The project runs art and education activities to build a sense of self-worth (self-esteem), self-concept, empowerment and emotional control (self-efficacy). Children attend sessions for 6 months (50+ sessions),	The intervention was led by a team of trained and supervised youth ambassadors.	1. Children attending the intervention programme displayed significantly higher self-efficacy than children who did not. 2.No statistically significant differences were found between those who attended the intervention and those who did not score on the CDI (depression), the SDQ (emotional and behavioural problems) and the Rosenberg Self Esteem Scale	No long-term follow up reported. Follow-up was done immediately after the intervention ended



## **4.4 RESULTS**

### ***4.4.1 General description of the studies***

The articles that were part of the systematic review focused on studies of various intervention strategies for children affected by HIV and AIDS in Kenya, South Africa, Rwanda and Uganda. Three studies were conducted in various provinces around South Africa (Bhana et al., 2014; Boon et al., 2009; Mueller et al., 2011). Three studies were conducted in Uganda (Han et al., 2013; Karimli et al., 2019; Kumakech et al., 2009), and the remaining two (Betancourt et al., 2014; Goodman et al., 2014) were conducted in Rwanda and Kenya, respectively.

The interventions described in the studies had three major focus areas of intervention such as peer-support (Kumakech et al., 2009), community-based interventions (Boon et al., 2009; Goodman et al., 2014; Mueller et al., 2011) and family-based interventions (Karimli et al., 2019; Betancourt et al., 2014; Bhana et al., 2014; Han et al., 2013). The details of the studies conducted to assess the effectiveness of these interventions will be presented in the following section using the individual characteristics related to the RE-AIM framework.

### ***4.4.2 RE-AIM characteristics of the studies***

#### ***4.4.2.1 Reach***

Reach is an individual-level measure of participation that focuses on the characteristics of participants and whether the intervention reached the target population (Glasgow et al., 1999). This refers to whether the study describes the intended recipients of the intervention. All of the studies clearly described the intended recipients of the interventions. They were different target groups, such as children, parents and other caregivers of children affected by HIV and AIDS.

The target group for the interventions was the children alone, their parents/caregivers, or the whole family. The criteria for inclusion in the interventions and the participation rate were clearly stated in all of the studies, but only half (50%) reported on the representativeness of the target population (Goodman et al., 2014; Han et al., 2013; Kumakech et al., 2009; Mueller et al., 2011). However, most of the studies (87%) did report a high participation rate ranging between 70% and 91% (Betancourt et al., 2014; Bhana et al., 2014; Boon et al., 2009; Goodman et al., 2014; Han et al., 2013; Karimli et al., 2019; Kumakech et al., 2009). The highest participation rate was observed in the study by Han et al. (2013) conducted in Uganda, where 91% of the sample still participated 12 months after the intervention. Participant attrition is of concern for some of the studies. At least 75% of the studies (Betancourt et al., 2014; Bhana et al., 2014; Boon et al., 2009; Goodman et al., 2014; Han et al., 2013; Kumakech et al., 2009) reported on participant attrition, and the study with the highest attrition rate of 30% was the South African study of Xhosa speaking grandparents of Port Elizabeth (Boon et al., 2009). The reasons for non-attendance were mostly related to health problems, being out of town or work, death in the family, and child-minding responsibilities. The reporting on recipients, participation and attrition rate shows that these interventions were able to reach their target population.

#### *4.4.2.2 Effectiveness*

The effectiveness dimension focuses on assessing programs' positive and negative consequences (Glasgow et al., 1999). In assessing interventions, it is important to look at whether the intervention achieved its intended outcomes and what were unanticipated negative effects. At least two of the studies (Kumakech et al., 2009; Mueller, 2011) acknowledged that



there was no significant impact of the interventions noted. All of the studies reported on the positive outcomes of the intervention and on whether the interventions achieved the intended outcomes. There was no clear discussion on the negative outcomes or impact of any interventions except for the limitations of the studies. Some of the limitations mentioned relate to practical and financial resources, confounding variables (in the participant's environment) not accounted for in the study, indicators used to assess mental health which may not be contextually relevant, researcher bias and possible contamination by field workers.

Nevertheless, the results of the community-based interventions showed an improvement in the participants after the interventions (Boon et al., 2009; Goodman et al., 2014). The community-based pilot health education intervention positively assisted the grandparents in their caregiving responsibilities and increased their HIV and AIDS knowledge (Boon et al., 2009). The results of the other community-based intervention showed statistically significant differences in social, economic and health-related behaviours in families after attending the intervention (Goodman et al., 2014). The remaining 50% of the studies focused on family-based interventions and their impact on the physical and mental health of the children and their families/caregivers, as well as their economic status. All these studies reported an improvement in all key intervention outcomes, including mental health (Betancourt et al., 2014; Bhana et al., 2014; Han et al., 2013; Karimli et al., 2019) which in turn indicates a positive impact and effectiveness of the interventions.

#### *4.4.2.3 Adoption*

It is also important to examine the extent to which the studies report on the reception of the intervention by the organisation and participants and partnerships between organisations and

those who delivered the program. More than half (75%) of the studies gave a fair account of the adoption of the intervention by the affected organisations and communities studies (Betancourt et al., 2014; Bhana et al., 2014; Boon et al., 2009; Goodman et al., 2014; Mueller et al., 2011; Kumakech et al., 2009) except for Han et al. (2013) and Karimli et al. (2019). These articles also reported on the people that delivered the interventions as well as supervision that was provided to them by the researchers and existing senior staff from the partner organisations. This indicates that the organisations adopted the interventions, and the high participation rate is also an indicator of adoption by participants.

#### *4.4.2.4 Implementation*

Glasgow et al. (1999) describe implementation as the extent to which a program is delivered as intended. This was achieved by assessing whether the selected studies reported on intended interventions and the duration and/or frequency. All the studies provided a detailed description, duration and frequency of the interventions except for one study by Boon et al. (2009). All reported on whether the interventions delivered the intended aims and objectives. A variety of methods were used for delivery for all the interventions, including workshops, psycho-social exercises, training/education sessions, and individual and group sessions. The content covered in these interventions differed according to the aim of the intervention. None of the studies reported changes in the implementation of the interventions, which indicates that the interventions were delivered as intended. These studies stressed the importance of inclusion and participation of relevant stakeholders and communities in implementing the interventions.

#### *4.4.2.5 Maintenance*

The dimension of maintenance examines the extent to which the studies report on long-term effects as well as follow-up after the interventions. This refers to the “extent to which innovations become a relatively stable, enduring part of the behavioural repertoire of individual or organisation or community” (Glassgow et al., 1999: 1324). It is about the sustainability of the intervention over time, especially after the initial intervention is completed as well as the long-term effects of the interventions. Most of the studies (87%) discussed long-term follow-up that was done sometime after the interventions, and this was done up to 6, 12 and 24 months after intervention (Betancourt et al., 2014; Goodman et al., 2014; Han et al., 2013; Karimli et al., 2019). The remaining studies (Bhana et al., 2014; Boon et al., 2009; Kumakech et al., 2009) also did some post-intervention follow-up but only at 2 weeks, 3 months and 10 weeks, respectively. The follow-up on these studies revealed that the results observed immediately after intervention were still present long after the intervention. However, the studies did not report the indicators used for intervention follow-up. The information provided only stated the methodology used in the studies, predominantly Cluster Randomised Controlled Trials, Longitudinal, cross-sectional and cluster-randomised experimental studies with intervention and control groups. All participants in the intervention and control groups were initially assessed at baseline and post-intervention, except in the study by Goodman et al. (2014), where no baseline data was collected. The long-term follow-up after the interventions was completed indicates that the interventions generally impacted participants positively. It should, however, be noted that the reports were on the improvements that still existed, as had been observed during the last post-intervention follow-up on all the studies (Betancourt et al., 2014; Bhana et al., 2014; Boon et al., 2009; Goodman et al., 2014; Han et al., 2013; Karimli et al., 2019;

Kumakech et al., 2009) but there was very little mention of clear indicators used to assess long-term effects of interventions.

## **4.5 DISCUSSION**

As long as Sub-Saharan Africa remains the region with the highest number of HIV infections in the world (UNAIDS, 2022), there is still a need to scrutinize existing interventions or programs to evaluate what works and improve methods of interventions. The common element in all these interventions is considering the child's immediate impact in facilitating change. These interventions address two main issues: psychosocial support and empowerment of families of children affected by HIV and AIDS.

### ***4.5.1 Psychosocial Support***

Five out of the eight interventions focused on improving the psychosocial well-being and mental health of children affected by HIV and AIDS (Betancourt et al., 2014; Bhana et al., 2014; Boon et al., 2009; Kumakech et al., 2009; Mueller et al., 2011) with a particular focus on addressing social support for children by including their caregivers. Boon et al. (2009) used caregiver support by educating grandparents on HIV and AIDS information to help increase their caregiving proficiency, while the other two interventions addressed social support of children by including their families (Mueller et al., 2011; Kumakech et al., 2009). Two interventions specifically focused on improving children's mental health (Betancourt et al., 2014; Bhana et al., 2014) and used family-strengthening interventions to reduce mental health problems among HIV-affected children through improved child-caregiver relationships, family communication and parenting skills, HIV psychoeducation and connections to resources. The motivation behind these interventions could be attributed to the fact that HIV

diagnosis does not only affect the physical health of the people infected, but it also affects the whole family. Children living with HIV-infected parents have been identified in previous studies (Doku, 2010) as consistently demonstrating poorer psychosocial adjustment in their communities. Furthermore, Betancourt et al. (2013) and Doku (2010) concur that HIV and AIDS pose direct threats to children's mental health, resulting in poor psychosocial adjustment, and disrupted family functioning and well-being.

The results of the studies show that the focus of the interventions on social support resulted in improved relationships and communication between caregivers and children as well as lower levels of mental health problems in the children. This highlights the value of family-based interventions in improving family relations, resulting in decreased mental health issues. Lachman et al. (2014) also agree that parenting interventions that situate positive parenting within a wider ecological framework by improving child behaviour problems and caregiver depression might buffer against risks for poor child mental and physical health outcomes in families affected by HIV/AIDS and poverty. This means that encouraging positive relationships between caregivers and children in families affected by HIV reduces the risks of mental health problems in children.

The issue of HIV and AIDS has moved beyond being a medical problem and has shifted to include psychosocial elements. To contribute to the holistic management of HIV, the impact of HIV on the mental health of children in HIV-affected families needs to be better understood and attended to. This supports previous research (Sherr et al., 2016), which recommended that community-based interventions in settings that lack specialised mental health provision may be well placed to alleviate caregiver depression in the presence of HIV and may help to disrupt



adverse child outcomes. These psychological interventions may enhance coping and resilience in children affected by HIV and AIDS and decrease the psychological problems associated with being orphaned due to AIDS (Kumakech et al., 2009). The effectiveness of the intervention demonstrated by the two studies provides evidence for the success of psychosocial support and care for OVC. The remaining three interventions focused on improving children's psychological well-being through the economic empowerment of their families and will be discussed further in the next section.

#### ***4.5.2 Empowerment***

The remaining three interventions used empowerment approaches in addressing the needs of children affected by HIV and AIDS. Two of the economic empowerment interventions (Han et al., 2013; Karimli et al., 2019) focused on enabling families caring for AIDS orphans by creating economic opportunities for these families and ultimately promoting mental health. The other economic empowerment intervention (Goodman et al., 2014) combined income generation, cash transfer and microfinance approaches to OVC families by providing the families with business, health, hygiene, and agricultural skills. The results of two studies (Han et al., 2013; Karimli et al., 2019) revealed a significant positive impact of the interventions on the children's mental health and the other study (Goodman et al., 2014) also showed statistically significant changes in health and livelihood outcomes in OVC families following participation in the intervention. All of these studies clearly show the importance of using interventions that include the relevant people in the children's immediate environment. Goodman et al. (2014) further stress the importance of using partnerships with communities and multi-sectoral collaborations in the implementation of the interventions for OVC. These

results support earlier studies (Bhana et al., 2010) that reported on an intervention program called Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP) focused on establishing a strong community and institutional partnerships so that communities support prevention efforts and institutions. Once again, the findings indicate the importance of working in the child's environment by using community and family-based approaches to ensure a holistic approach and the success of the intervention.

The conclusion can thus be made that a family economic empowerment programme may relieve psychosocial distress among AIDS-orphaned children. The studies show that interventions aimed at enhancing the psychosocial functioning of children affected by HIV should focus on psychological support and include family economic empowerment through asset-building opportunities for families in poor resource communities (Han et al., 2013). This confirms that managing the physical symptoms of HIV and AIDS is not enough if other factors, such as the family's economic resources, are not considered in developing interventions for HIV-affected children and their families.

#### **4.6 IMPLICATIONS FOR PRACTICE**

The RE-AIM framework gives social workers important and practical information that can assist in designing and implementing future community-based intervention programs. Burke et al. (2015) argue that the RE-AIM framework's benefit is that it provides a guide for reporting intervention-related information that, if reported consistently, could have important implications for practitioners tasked with making decisions and recommendations for program planning, implementation and evaluation.

The SR revealed that sometimes intervention programs experience a high attrition rate of participants due to difficulties in their social circumstances, which may negatively affect the interventions' ability to *reach* the intended recipients. This indicates that when programs are implemented, social workers should consider the community's cultural context and its possible influence on intervention programs. Therefore, social workers need to be flexible regarding intervention settings (Isaacs et al., 2018) and adapt interventions to fit the context of communities where implementation will take place. This will ensure that the intervention reaches the intended participants.

The SR also showed the importance of long-term follow-up to ensure the *effectiveness* of interventions. In all the studies reviewed in the SR, the changes reported immediately after intervention reflect short-term results. A true reflection of the effectiveness of programs needs to be measured at least 6 – 12 months post-intervention (Glasgow, Vogt, & Boles, 1999), which would indicate the long-term impact of interventions. However, caution should be exercised when reporting on the effectiveness of interventions, as the process of tracking effectiveness becomes burdensome and unproductive without reliable measures that capture the benefits of the intervention (Shaw et al., 2019). Therefore, social workers should ensure that follow-up and evaluation plans are incorporated into the initial planning of interventions to indicate how effectiveness of interventions will be measured clearly. Social workers need to ensure that evaluation not only focuses on what worked but should also evaluate what did not and the reasons thereof. This will assist in identifying gaps, resolving existing problems in intervention and planning for changes.

*Adoption* of interventions by organisations and communities was reported because the interventions used the existing staff in the organisations who were already familiar with the community. People were trained on the relevant skills needed to facilitate interventions where there was no existing staff. This proved beneficial for all involved as these facilitators are familiar with the context of the community where the intervention occurs. Estabrooks et al. (2008) concur that the inclusion of a variety of community-based organisations in the planning of a program helps develop interventions that are attractive to both community members and professionals who may deliver such programs. The involvement of relevant stakeholders and the community is a very important aspect of program planning and implementation as it ensures approval and, ultimately, the success of intervention programs. Social workers must collaborate with community members and other relevant parties to ensure that they are part of the implementation of the intervention. This will ensure that the communities adopt the interventions if they are part of the implementation.

No major changes were reported in the planned *implementation* of the programs reported in the SR. This raises concerns about the interventions' adaptability to fit the participants' context. Isaacs et al. (2018) argue that a flexible intervention or programme, which can be adapted for a particular context, would be more appropriate and effective. Confounding factors such as the role of culture, influences of the family and the environment were not considered when discussing the programs' impact. In the African context, it is important to consider the impact of culture in communities, experiences of oppression and effects of poverty, as the 'one size fits all' approach will not work in different contexts. Most of the studies in the SR did not go into detail on the role of traditional leaders and healers in implementing the interventions,

except for Goodman et al. (2014). Traditional leaders and healers often play a very significant role in the overall management of illnesses within most African communities, for which HIV and AIDS are no exception. A study by Betancourt et al. (2014), which focused on mental health problems of CABHA, revealed that measures derived from standard western criteria are frequently based on conceptual models of illness or terminology that may or may not be appropriate for diverse populations. It is thus important for social workers to understand the structures in communities and the general meanings that communities ascribe to illnesses before attempting to implement interventions. This indicates that there is a need for cultural sensitivity and awareness of diversity by social workers. The likelihood of the adoption of interventions by communities is high if there is respect and understanding of the cultural context of the communities by social workers.

The results reported on the *maintenance* of interventions, but the indicators used to assess long-term effects were unclear. The reviewed studies did not mention what happens to the communities and participants once the studies are concluded. A definite conclusion thus cannot be made on the lasting effects of the interventions. Still, the follow-up done immediately after the intervention is worth acknowledging as evidence of the short-term effectiveness of interventions. According to Mwaikambo et al. (2011), positive short-term programme outcomes are also indicative of a programme achieving its goals, thus, should not be immediately disregarded. However, Thurman et al. (2016) caution that a one-year follow-up post-intervention may be too short to capture the full range of potential program effects. Practitioners thus need to ensure that when planning intervention programs, long-term follow-



up should be included as this will ensure lasting effects of intervention and provide an opportunity for evaluation.

#### **4.7 CONCLUSION**

Although the interventions identified in the study cannot be motivated as best practice models for CABHA, the RE-AIM framework used in the SR is encouraging to use as a tool for evaluating interventions. The results show that focusing on the child alone as the centre of intervention is insufficient and may be ineffective if other factors impacting the child are not considered. The scourge of HIV and AIDS has moved far beyond being a health issue. Interventions, therefore, should include other factors such as family economic empowerment and community-based psychosocial support. The RE-AIM framework highlighted that inclusion of the community and other stakeholders in intervention delivery plays a positive role in the success of interventions for CABHA. Practitioners must be flexible to the socio-cultural context of the communities where interventions are implemented. The lack of long-term follow-up in the studies indicates a need for practitioners to ensure the maintenance of the effects of interventions when planning intervention programs.

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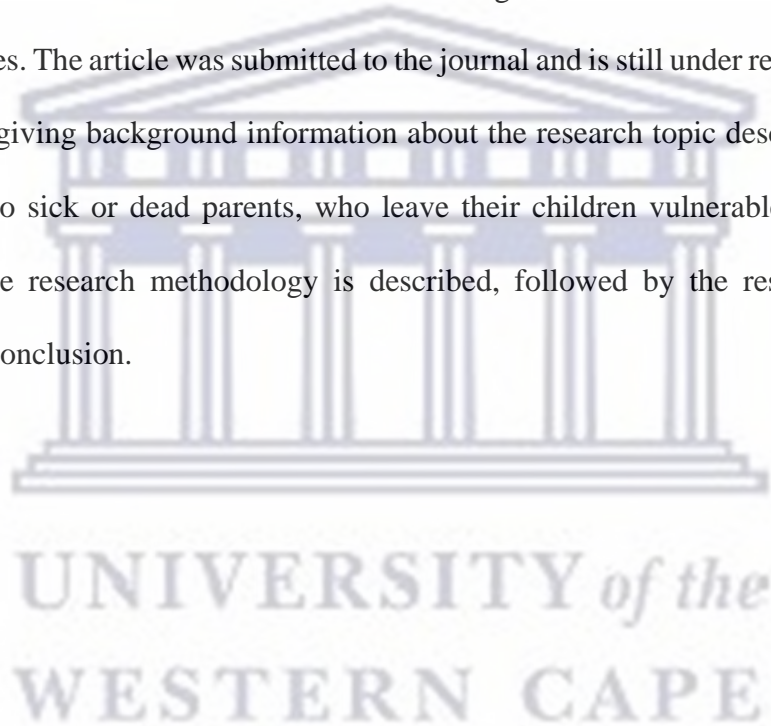
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## **CHAPTER 5**

### **A NEEDS ASSESSMENT FOR SOCIAL WORK INTERVENTIONS FOR CHILDREN AFFECTED BY HIV AND AIDS**

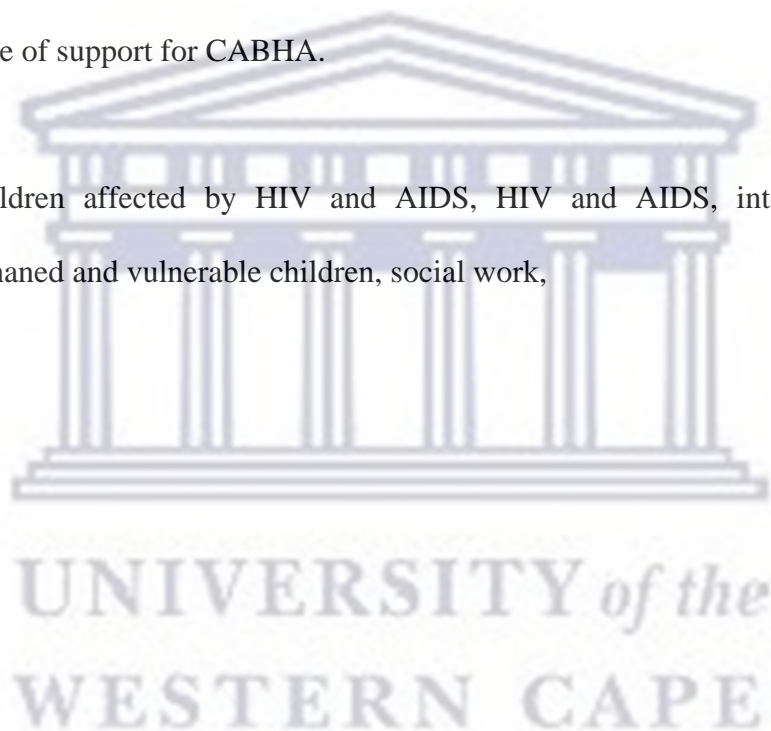
This chapter focuses on describing the study's results, which focused on identifying and describing the intervention models used when working with children affected by HIV and AIDS. The chapter is written in article format following the Social Work/Maatskaplike Werk Journal guidelines. The article was submitted to the journal and is still under review. The format article starts by giving background information about the research topic describing how HIV infection leads to sick or dead parents, who leave their children vulnerable and in need of intervention. The research methodology is described, followed by the results, discussion, limitations and conclusion.



## **ABSTRACT**

South Africa has very little information available on the type of interventions to reinforce the care and support provided to children affected by HIV (CABHA). This study aimed to explore existing interventions provided to CABHA and the experiences of social workers in implementing interventions. Findings indicate that interventions are a continuous and collaborative process between social workers and stakeholders. A proper needs assessment should be done before implementing interventions to ensure they benefit the children identified as needing intervention. Community-based interventions should not be underestimated as a significant source of support for CABHA.

**Keywords:** Children affected by HIV and AIDS, HIV and AIDS, intervention, needs assessment, orphaned and vulnerable children, social work,



## 5.1 INTRODUCTION

Children affected by HIV and AIDS (CABHA) are described as those “living with HIV, as well as those whose well-being or development is threatened by HIV because they live in HIV-affected households and communities” (UNICEF, 2011). These children are often vulnerable as they become caregivers to HIV-positive parents who are too ill to care for them. Sometimes, these children may end up orphaned when the parent dies of AIDS-related illness. UNICEF (2022) estimates that a total of 14.9 million children worldwide have lost one or both parents due to AIDS-related causes. The absence of a caregiver thus may leave the children at risk of exploitation, neglect, and needing care. This adds pressure on most government resources, already stretched due to the increasing number of HIV-infected persons and the demand for HIV treatment. The global community and individual countries have made progress towards addressing the needs of HIV-affected children and families. Still, support has most often been delivered through targeted programs which do not fully meet the needs of CABHA (Kidman & Heymann, 2016). UNICEF (2016) advocates for global solidarity in the AIDS response that must include the most vulnerable children and women if AIDS is ever to become an issue of the past.

Statistics South Africa (Stats SA) (2020) reports a decline from 12,9 deaths per 1 000 people in 2002 to 8,7 deaths per 1 000 people in 2020 (Stats SA, 2020). This decline is attributed to the increased access to Anti-Retroviral Treatment which means that people infected by HIV live longer lives. Li et al. (2014: 2052) state that “as improved treatment strategies continue to prolong the lives of parents living with HIV, more children will have to adopt caretaking roles and learn to cope with shifts in family structure, financial deprivation and stigma”. This

highlights a serious development of the problem of OVC and child-headed homes. These children are more likely to experience negative outcomes due to their inability to access essential resources such as education, healthcare and social services. To deal with the increasing burden of child-headed homes, there is a need for a united global response to the AIDS epidemic and interventions that include children orphaned and made vulnerable by AIDS.

Visser et al. (2015) argue that during the past decade, various interventions have attempted to address the diverse needs of OVC. Several interventions have been implemented across some African countries (Bhana et al., 2014; Goodman et al., 2014; Han et al., 2013; Karimli et al., 2019; Mueller et al., 2011) to support OVC and CABHA were included as part of these interventions. However, it is unclear how these interventions cater to the specific needs of CABHA as these interventions often focus on general issues affecting OVC. The structure of the interventions often depends on the needs and resources available in the community where these are being implemented. Still, very little information is reported on the social worker's role.

Furthermore, section 54 of the Children's Act 38 of 2005 (RSA, 2005) identifies children needing care as requiring social work intervention but refers to children in general and not specifically to CABHA. The literature on social workers' role in interventions for CABHA is very scant. There is extensive literature on the challenges faced by children affected by HIV, but disproportionately less is known about effective interventions to support children and families (Richter et al., 2015). Previous research (Mann et al., 2012) recommended the need for better information on the kinds of support and interventions in place to strengthen the



emotional, physical, economic and social care that families and communities provide to children living with and affected by HIV. The focus of the study was thus to explore the current interventions provided to CABHA by various organisations and the experiences of social workers in implementing interventions.

## **5.2 METHODOLOGY**

The study used a qualitative research approach with an exploratory research design, and the data were collected in two stages using semi-structured interviews. Qualitative research is a research methodology where researchers are interested in knowing how people understand and experience their world at a particular time and in a particular context (Merriam & Grenier, 2019). Qualitative research was applied to this study as this methodology allows the researcher to explore the problem being researched and to give detailed explanations based on the responses gathered from participants. In qualitative studies, researchers “enter the setting with open minds, prepared to immerse themselves in the complexity of the situation and interact with the participants” (Fouché et al., 2021:40). The interviews used to collect data provided the researcher with the opportunity to engage with the participants and gain in-depth information. An exploratory research design was deemed appropriate for the study since this type of research design, according to De Vos et al. (2011), is normally used when there is no past data or the researcher only has a few studies for reference.

### **5.2.1 Participants**

**Stage one** of the selection process was done through purposive sampling, as the researcher had to select organisations that met the specific criteria for inclusion. Purposive sampling comprises elements that contain the most typical attributes of the population being studied (Fouché et al.,

2021). The organisations that were chosen had to meet the following selection criteria: An organisation that works with general OVC and those made vulnerable by AIDS; provides psychosocial support programs aimed at CABHA; have designated persons who can explain the programs of the organisation. Seven organisations were identified within the Cape Town Metropolitan area, and 13 participants were interviewed from these organisations. The demographic details of the organisation are summarised in Table 5.1.

**Table 5. 1 Demographic Profile of the Organisations**

<b>Organisation number</b>	<b>Pseudo name</b>	<b>Number of participants</b>	<b>Type of organisation</b>	<b>Job title</b>
1	AT	1	NGO	Program Coordinator/Social worker
2	GU	3	NGO	Social worker Professional nurse Youth Worker
3	H4H	2	NGO	Social workers
4	LH	3	NGO	HAST coordinator OVC coordinator HAST Councillor
5	NCS	1	NGO	Program coordinator
6	UWL	1	NPO	Director
7	YB	2	NGO	Youth counsellors

Most of the organisations were Non-Governmental Organisations (NGOs), and one was a Non-Profit Organisation. The participants that represented the organisations were people

responsible for either managing, coordinating or facilitating interventions for OVC or CABHA in their organisations and had different job titles depending on the structure of each organisation. Some organisations had one person responsible for the overall management of the organisation and its programs, while others had teams responsible for managing the different programs offered. For example, organisations 1, 5 & 6 each had only one person representing their organisation. Two of these people occupied the roles of the program coordinator, and the other participant occupied the role of director. Teams of people represented the remaining organisations; some came in pairs (social workers and youth counsellors), while others came in groups of three consisting of professional staff. Out of the total number of 13 participants, there were at least three social workers.

The participants of **Stage two** of data collection were strictly social workers who were identified through a snowball sampling method. Snowball sampling is when the researcher recruits the participants by referral from other participants who are already participating in the study. According to Fouché et al. (2021), in snowball sampling, the participant is requested to refer others with similar experiences to gain information on similar persons who could make up the sample. Participants in organisations that participated in stage 1 were approached and asked to refer to social workers they usually work with who provide interventions to CABHA. Once the social workers had completed their interviews, they were requested to provide a recommendation of other social workers they deemed meeting the study's criteria. The inclusion criteria for the study were social workers who were:

- registered with the South African Council of Social Service Professions
- working with children under the age of 18,

- working/have worked with OVC and CABHA for a minimum period of one year.

15 social workers participated in the study. The demographic profile of the social workers is detailed in Table 5.2.

**Table 5. 2 Demographic Profile of the Social Workers**

Social worker number	Age	Gender	Language	Number of years qualified as a social worker	Number of years working in current organisation	Number of years working with CABHA
1	44	F	Xhosa	19	9	15
2	39	F	Xhosa	2	1	1
3	47	F	English	24	2	15
4	49	F	Xhosa	12	2	5
5	31	F	Xhosa	7	1	1
6	51	F	Afrikaans	29	5	18
7	46	F	Afrikaans	5	1	1
7	25	F	Afrikaans	2	1	1
7	39	F	Afrikaans	12	1	12
7	45	F	English	1yr11monts	1yr 11months	1
7	25	F	Afrikaans	2 ½ y	1 ½ yrs	1
7	37	F	Afrikaans	12	3	1
7	59	M	English	32	6	1
7	36	F	Afrikaans	10	9	9
8	49	F	English	24	7	7

All the social workers were interviewed individually except for one organisation. Eight social workers were interviewed as a group due to operational demands that made it impossible for them to be available individually at separate times. The social workers in this organisation are

allocated the same number, seven. The responses from this group are labelled SW7 since they were captured as part of the focus group interview. Most of the participants in the sample were female (n=14), with only one male participant. The age range was between 25 and 59 years, with the oldest being a male participant. The reason for this can be attributed to the fact that there were no male social workers in all the organisations that were approached. Just over half (n=8) of the social workers had more than ten years of being qualified as social workers. Five social workers indicated that their social work experience did not directly relate to children affected with HIV but focused on general OVC. At the same time, the remaining group had some experience with children affected with HIV.

### **5.2.2 Data Collection**

Data were collected in two stages. The first stage focused on interviewing service providers to identify and describe the intervention models used by various organisations working with CABHA. The service providers selected by the organisations were people they felt would best represent them, and these were different categories of staff, including social workers in some organisations. The second stage consisted of interviews with only social workers, and it aimed at exploring the experiences of social workers using interventions aimed at CABHA. Each stage had a different set of participants that were interviewed. The interview type depended on the number of people available for the study in an organisation. In both stages of the study, data was collected through either one-on-one interviews or focus groups with participants from organisations that provide services to CABHA. In organisations with one participant, one-on-one interviews were used, and more than two participants were available. Data were collected via focus group interviews. Interviewing participants in groups allows the researcher to engage



participants in a discussion and gather diverse perspectives (Geyer, 2021). Permission was sought from the participants' employers for the researcher to gain access. Once permission was granted, the researcher contacted the participants, and they voluntarily agreed to participate in the interviews. Participants were assured that the information shared would be kept confidential and were made aware of their right to withdraw from the study at any given point in time. The option of counselling by a registered social worker was offered to participants if they needed it after participating in the study, but none of them felt the need to use it. Interviews took place in venues chosen by the participants, which was their place of employment in all the instances, and the interviews lasted between 60 to 90 minutes. All the interviews were conducted in English as all the participants were comfortable conversing in English.

### ***5.2.3 Data analysis***

The data from the interviews were recorded, transcribed and analysed through thematic analysis. Creswell and Creswell (2018: 193) urge researchers to “look at qualitative data analysis as a process that requires sequential steps to be followed, from the specific to the general and involves multiple layers of data analysis”, involving five steps of data analysis. The first step is about organising and preparing data for analysis. This involved going through the transcripts, giving pseudonyms and linking them to fieldnotes made during the interviews. As explained in the previous section, there were 15 social workers, but there were 8 transcripts due to the different interviewing methods used. Each transcript was allocated a number between 1 and 8, and the transcript where a focus group was used was labelled as number 7. The second step involved reading through all the data to get a sense of all the information in the transcripts, trying to see if participants answered the questions in the interview schedule

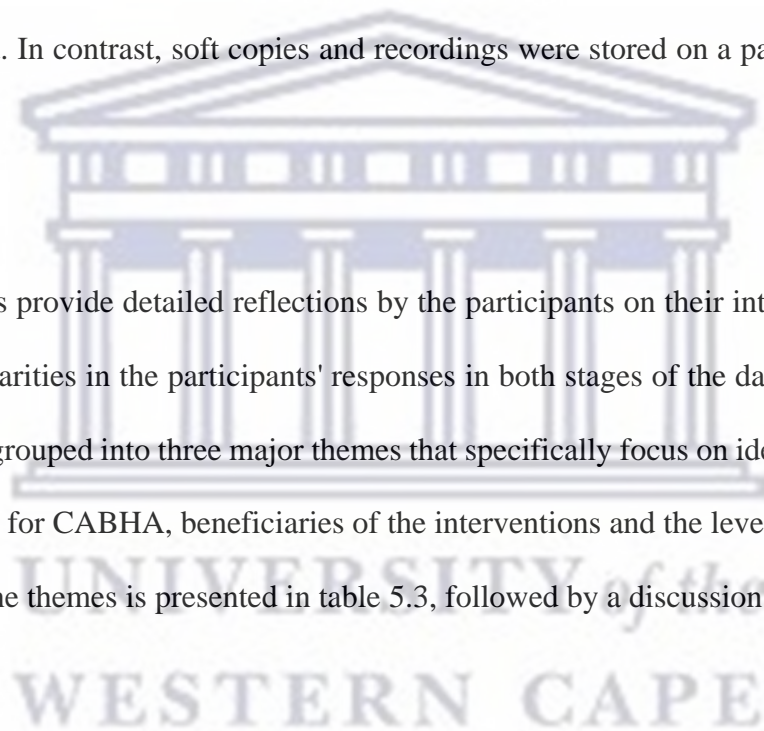
and understanding the responses. This stage involved going back to the interview schedule, looking at the questions in the interview schedule, and comparing them to the responses in each transcript to check if the participants answered the questions. The responses in the transcripts were compared to the field notes to check if the information corresponds. Where there was uncertainty or gaps, the researcher returned to the recordings to check if any information was missed. The third step is where the coding process starts. This is where similarities in the participants' responses were noted, and this was done by creating a table to write down the information. This table contained responses given by participants to each question from the interviews. Where common elements were found in responses to each question, a keyword that summarised the participants' main point was noted. These keywords helped compare participants' responses and similar group responses to check if participants were alluding to the same thing. The differences in responses were also noted down. The fourth step was made by summarising the common elements identified to generate a description of the words described in the third step. This was done to ensure that there was no repetition and to merge some of the keywords or separate them further into different ones. This process resulted in developing themes and sub-themes from the participants' responses. The fifth step involved checking for interrelating themes. This is the process of rechecking if some of the themes identified could be merged or separated further and deciding which parts become sub-themes or categories. Some of the words used for subthemes were either too general or could be interpreted differently, which is why categories were added to clarify the subthemes. These became the final themes that were deemed appropriate for the study. An explanation of the themes is given in the results section.

### **5.3 ETHICAL CONSIDERATIONS**

Permission to conduct the study and ethical clearance was granted by the Department of Research Development of the University of the Western Cape (UWC), with an ethical clearance number of 15/6/30. All information about the study was shared with the participants before participating to discuss the aim, objectives, risks, benefits and questions that participants may have. Participation in the study was voluntary, and participants were allowed to withdraw from the study at any point should they wish to do so. All personal information of the participants was kept confidential, and the hard copies of information shared were kept in a locked cupboard. In contrast, soft copies and recordings were stored on a password-protected laptop.

### **5.4 RESULTS**

The study results provide detailed reflections by the participants on their interventions. There were some similarities in the participants' responses in both stages of the data collection. The responses were grouped into three major themes that specifically focus on identifying the need for interventions for CABHA, beneficiaries of the interventions and the levels of intervention. A summary of the themes is presented in table 5.3, followed by a discussion.



**Table 5. 3 Summary of Themes and Sub-themes**

<b>Themes</b>	<b>Sub-themes</b>	<b>Categories</b>
<b>Theme 1: Identification of CABHA in need of intervention</b>	1. 1: Assessments	1.1.1: Home visits
	1.2: Referrals	1.2.1: community healthcare workers
		1.2.2 caregivers and communities
	1.3: Awareness- raising in the community	
<b>Theme 2: Beneficiaries of the interventions</b>	2..1 OVC	
	2.2 Family	
	2.3 Caregivers	
<b>Theme 3: Levels of intervention</b>	Individual	Counselling
	Group	Treatment groups, education groups, family support
	Community	Networking & multisectoral collaboration

#### **5.4.1 Identification of CABHA in need intervention**

One of the questions that participants were asked was to explain the type of intervention they provide to CABHA. It became apparent that most responses pointed towards the importance of identifying these children needing intervention before doing the actual work. The participants reported that they follow certain processes that help identify CABHA in need of intervention, including assessment, referral and awareness raising.

#### 5.4.1.1 Assessment

The participants identified **assessment** through home visits as their primary method of identifying their clients. Some assessments are done informally through information provided by non-professional staff who conduct home visits and discover that there are OVC in those homes who need care. Social workers formally conduct some assessments.

One participant reported an informal type of assessment that is done when visiting the parents at home and said:

*“Through my assessment is where I identify that the parent is HIV positive, not only working with children affected by HIV” (AT).*

Similarly, another participant mentioned that:

*“The carers go out into the community to go do home visits as well. So, they might come there to take the granny’s blood pressure because they were referred from hospital, this person needs a weekly blood pressure or sugar test. When you come there, you find the situation is of such a nature that these children are vulnerable or they are orphans, their parents left them or died from HIV/AIDS”. (LH)*

The home visits alluded to in the quotes above provide opportunities to identify CABHA through assessment. Assessment involves “gathering and interpreting information to understand a person and their circumstances; the desirability and feasibility of change and the services and resources which are necessary to effect it.” (Milner et al., 2015:1). The participants’ responses suggest that the participants do what literature calls a ‘needs assessment’ (Zastrow, 2017) or sometimes referred to as a ‘needs analysis’ (Kirst-Ashman & Hull, 2012). A needs assessment is a “systematic analysis of client problems and issues to



determine clients' needs and develop problem-solving strategies" (Zastrow, 2017: 501). A needs assessment requires careful planning to understand the problem at hand thoroughly. It assesses how the problem affects clients' well-being and whether it is enough to merit intervention (Kirst-Ashman & Hull, 2012). This will ensure that the planned intervention addresses the identified problem and that the organisation provides relevant services to the clients.

The study also highlights home visiting as an assessment category to explain how some assessments are conducted. The participants identify home visits as a common practice for assessing children in need. Thurman et al. (2014) argue that community-based home visiting is a common mechanism for providing support services to HIV-affected families. The home visits are either done solely for assessment by social workers or, in some instances, they form part of the daily duties of community workers who may accidentally come across a child needing care while visiting a home for a different purpose. The assessment done by social workers is often referred to as a formal assessment, while the 'accidental' assessment done by other service providers is called an informal assessment. The participants' responses below indicate formal assessment:

*We also do home assessment, train and refer foster parents (SW5)*

*We do door to door intervention, HIV prevention in the community, where HIV workers go to the community to clients' homes. (SW 5)*

Furthermore, the informal assessment is explained by the participant who said

*You pick up the child that is at risk there (during home visits) and the life skills educators then refer them to the OVC programme. (LH)*

Home visiting is a popular component of programs for HIV-affected children in Sub-Saharan Africa, but its implementation varies widely (Kidman et al., 2014). Similarly, Betancourt et al. (2014) agree that home visiting enhances access by allowing counsellors to reach many HIV-affected children at once and decreases barriers that many vulnerable families face when trying to access healthcare or centre-based psychosocial interventions. On the contrary, Thurman et al. (2014) argue that home visiting is ineffective. This means that there is a need for a thorough and more structured assessment to be done that does not only depend on home visiting. Regardless of who makes the initial contact, it is clear from the above statements that the primary practice in most interventions is an assessment to determine the actual needs of CABHA. The results also show that if other service providers or non-professional staff have done the informal assessment, a referral to the social worker is done for further assessment. This means that a social worker does the formal and final assessment. One of the participants reflected that:

*“when they identified there is something that needs social work intervention, they send a referral, so it comes straight to us. (SW1).*

The Children’s Act 38 of 2005 (RSA, 2005) requires that children in need of care be referred to a designated social worker for investigation and intervention. Referral to other service providers with the necessary expertise in the field is very important because, according to Thurman et al. (2014), home visitors who are not formally trained have limited counselling skills. Even their psychological challenges may inhibit their ability to address clients’

emotional needs. With their limited counselling skills, it thus becomes very important for the non-professional staff who conduct informal assessments to refer CABHA to a social worker for a formal assessment and intervention in line with the Children's Act and to ensure that there is proper follow-up. Kidman et al. (2014) highlight the need for programs serving HIV-affected families to add focused psychological interventions to supplement traditional home visiting.

#### *5.4.1.2 Referrals*

As mentioned above, referrals were also identified as a sub-theme and an important part of identifying CABHA in need of intervention. The most common referrals of CABHA identified by the participants come from healthcare facilities such as clinics or hospitals. Still, there were also referrals from other service providers that were identified. The statements below show the participants' explanations about referrals.

*The process is that we get children referred by clinics, by schools and some are brought by their own parents. (SW8)*

*The community people, the caregivers and manager of community centre refer clients. (SW2)*

*We receive referrals for children affected where the mother is in the hospital, or the parent can't disclose to the children about HIV-positive status (SW 1).*

The participants' statements above reflect the importance of the referral process to ensure that CABHA receives the necessary assistance. Kirst-Ashman (2017) stresses the importance of

referral to other professionals when these others have the knowledge and skills necessary for making progress with clients.

#### *5.4.1.3 Awareness raising*

Awareness in the community is the third process of identifying children in need of care, which relates to self-referrals that come due to the organisations raising awareness and publicizing their services in the community. Organisations identified awareness raising done through different mediums of communication as having a significant role in recruiting community members to take part in the interventions or referring those in need of intervention. The participants reported that:

*We are based at the clinics, we made boards on the clinics to make people aware, we give information to people, so that people can be aware of us. (YB)*

*Usually, it's word-of-mouth like if we work in the community there's always word-of-mouth that's going out (GU)*

*Handing out flyers in the community so that there's just awareness that this programme will be happening for the children and the teenagers. (LH)*

The method of raising awareness differs for each service provider as each uses resources they have at their disposal to ensure that the public knows about their services. Raising awareness in the communities about interventions aimed at children affected by HIV means that the community members are indirectly involved in the interventions and are part of the recruitment process. This may create a sense of trust in the community and ensure that community members take ownership of the interventions happening in their communities (Tumwesige et al., 2021).

This awareness raising makes it easy for the information to reach the potential beneficiaries because community members are most likely to spread the word to those in need of the services. Kumakech et al. (2009) and Mueller et al. (2011) advocate for the importance of the participation of affected communities in interventions that affect CABHA in the communities as this ensures that the communities accept those interventions.

#### ***5.4.2 Beneficiaries of the interventions***

The participants explained that after identifying the need for intervention, they need to decide who the beneficiaries of the intervention will be. All the participants identified children as their main beneficiaries of interventions, and the difference was in how the programs were implemented and whether they included other people in interventions. Two types of beneficiaries identified are CABHA and families.

##### *5.4.2.1 Orphaned and Vulnerable Children (OVC)*

Organisations mostly use the term Orphaned and Vulnerable Children (OVC) to describe the type of children that are beneficiaries of interventions implemented. Some participants explained that they include CABHA as part of the services offered to all OVC while others explained that their services are specifically aimed at CABHA. The participants. When explaining who the beneficiaries of the interventions were, the participants said:

*We provide a safe home and environment and family to orphans and vulnerable children (H4H)*

*Our activities focus on children and family, we're doing HIV prevention and doing foster placements. Targeting OVC youth and families around the community. (UWL)*



*In our society there is a lot of children who are living as orphans with parents who died because of HIV and AIDS (SW7)*

The term OVC is described by Wood & Goba (2011:276) as referring to “any child whose level of vulnerability has increased as a result of HIV and could include any child under the age of 18 who falls into one or more of the following categories: has lost one or both parents or experienced the death of other family members; is neglected, destitute, abandoned or abused; has a parent or guardian who is ill; has suffered increased poverty levels; has been the victim of human rights abuse; is HIV positive themselves”. According to the above description, CABHA meets the criteria to be called OVC as they may be experiencing a parent/caregiver who is ill or died due to HIV and may end up destitute or neglected due to the absence of a parent/caregiver. Research shows that it is not clear that there are particular difficulties faced by CABHA that require an inclusive approach.

Even though all the interventions are aimed at benefiting mainly the OVCs, the organisations had different ways in which they implemented their programs. Most of the participants explained that their organisations do not separate CABHA from the rest of OVC as these children are also vulnerable due to parental HIV illness/death but may have specific needs that are different from the rest of OVC. They acknowledged the different needs that CABHA have compared to the rest of the OVC, such as Anti-retroviral (ARV) medication for those infected. The participants expressed the inclusive nature of their interventions as follows:

*Due to the demands of the children who are not positive but in need of protection and safety, it is why we're taking any child now (SW 4)*

*We don't really give attention to that because in the children's act it doesn't say differentiate between a HIV and non- HIV child, so we look at the best interest of the child always (SW 7)*

*Beneficiaries are sometimes infected, but all are affected, therefore, we sometimes get people who just want to be in the know and we do take such people under our care, and we try by all means to take everyone. (YB)*

*The aim is looking at OVC, this OVC can either be HIV negative or HIV positive and provide holistic issues or holistic approach in making sure that all their needs are being met. (NCS)*

This means that the organisations do not discriminate between HIV-positive and negative children as all children are affected by HIV regardless of their HIV status.

#### *5.4.2.2 Families*

Furthermore, in explaining the inclusive nature of their interventions, the participants also mentioned including other family members such as parents or caregivers. The following responses were given regarding the inclusion of family members in the intervention:

*We encourage parents to go to workshops of parenting (SW1)*

*We work with parents as well, we have a disclosure support group (SW6)*

*We have a programme for men, we call it 'life skills for men and young men'. It's a mentoring programme because you know that men often feel that it's difficult for them to speak out. (AT).*

Visser et al. (2015) explain that in Africa, orphans and vulnerable children are often cared for in extended families or child-headed households and are vulnerable to poverty. Thus, interventions must include family members who may not necessarily be the immediate family.

Still, other family members may also be included in interventions, as HIV in the family affects everyone. Sherr et al. (2014) agree that this is especially true in sub-Saharan Africa for younger children. The care input comes from the wider extended household and may not be vested exclusively in a single caregiver. This shows the importance of considering the extended family context when providing services and interventions for CABHA and that interventions for CABHA are not isolated but are included as part of general interventions to OVC. Involving the family in interventions ensures that the relevant and affected systems within the family are also part of the solution. Furthermore, this ensures the long-term sustainability of the support and coping methods in the absence of the social worker and after the intervention has ended.

#### ***5.4.3 Levels of intervention***

The participants reported that they approach their service delivery at different levels of intervention, depending on the needs of their clients, and these levels of intervention identified were micro (individual) mezzo (group) or macro (community) levels.

##### ***5.4.3.1 Micro Level***

The most common intervention mentioned is the micro level which involves working with an individual client. Zastrow (2017: 42) explains that micro practice is aimed at “helping individuals on a one-to-one basis to resolve personal and social problems and may be geared to help clients adjust to their environment or to changing certain social and economic pressures that adversely affect them”. In explaining the type of counselling services that they do, the participants reported that:

*Psycho-social service is about counselling for kids, but we also support families, we also have disclosure counselling. (GU)*

*We also give the ongoing support because the children (CABHA) are growing so they go to a certain age of becoming teenagers, so they need to get the (correct) information*

*I do individual counselling for children and some families. (SW 6)*

*We also run therapeutic counselling for them individually, because of their age, early childhood, I use a lot of play therapy.’ (SW 4)*

*The child would share that there is violence at home, or the child has been raped.*

Children affected by HIV and AIDS, including “both those orphaned by AIDS and those living with HIV/AIDS, often find themselves at the intersection of HIV/AIDS, poverty, and mental health challenges: (Tumwesige et al., 2021:2). The issues highlighted by the participants indicate that CABHA is often faced with problems that affect their emotional well-being and requires for them to receive professional counselling. These are problems that mainly affect CABHA as they are exacerbated by the vulnerability caused by being affected by parental HIV. Previous studies (Breckenridge et al., 2019; Nabunya et al., 2019; Schenck, 2009; Sheer et al., 2016; Tucker et al., 2016; Visser, 2015) have shown that children affected by the caregiver and household HIV often face adverse outcomes in relation to their psychological well-being. Furthermore, children experience increased levels of distress and anxiety and may suffer a variety of psychological reactions following the disclosure of HIV status and maternal illness (Murphy et al., 2015; Richter, 2004; Richter et al., 2009;) and this may subsequently affect the present future functioning of HIV-affected children. When children’s level of functioning is affected, the social worker needs to intervene and provide counselling to assist the child in adjusting to their changing environment to deal with the pressures that adversely affect them.

These counselling issues mentioned by the participants are issues that contribute to the vulnerability of CABHA. Murphy et al. (2015) argue that the risk for psychosocial maladjustment in children living with an HIV-positive parent extends through late childhood into early to middle adolescence. This indicates that there are long-term psychological consequences for children affected by parental HIV, which thus requires interventions to assist these children in dealing with those issues.

#### *5.4.3.2 Mezzo level*

Participants reported that when dealing with clients who are CABHA, it becomes necessary to bring together groups of CABHA that have similar experiences and provide interventions at the group level. Interventions provided with groups are sometimes referred to as the mezzo level of intervention. Mezzo level of intervention seeks to facilitate the intellectual, emotional and social development of the individual through group activities (Zastrow, 2017: 42). The participants highlighted different types of group activities that they conduct with the CABHA of different age groups and the type of groups facilitated depends on the needs being addressed. Participants explained the reasons for group intervention as follows:

*We work directly with the kids, those affected and infected. What we found is that as the kids get older, they start wanting to know why they must take tablets always and that creates a stigma which we try to work around dealing with that. (SW 3)*

*There is fear attached to HIV, they meet other children that are HIV positive, they understand that they are not alone in this, it's not the end of the world if you're HIV positive. (SW 4)*



The information explained by the participants about the focus of the groups suggests that the type of groups conducted with CABHA are treatment groups since the focus is on helping them deal with HIV stigma and fears associated with HIV. Previous studies (Nabunya et al., 2019; Visser et al., 2015) identify stigma as a common experience that CABHA goes through in communities and other social spaces, which often lead to mental health issues such as stress and anxiety. Popa (2017) explains that treatment groups target to treat and heal their members' socio-emotional needs and aim to get together persons with similar needs. According to Popa (2017), the functions of treatment groups can be divided into the following categories: socialisation, recreational, educational and self-support or mutual support groups. The type of treatment group identified in the study is mutual support groups. Mutual support groups are meant to assist members in overcoming stressful life situations. Popa (2017:51) explains that these groups' benefits are “the mutual help offered between members, support to solve different issues and new approaches to resolve problems”. Mutual support groups, therefore, provide a space for CABHA to share their experiences with other children who have gone through similar circumstances. Previous studies (Kumakech, 2017) suggest that peer-group support intervention has a significant impact on helping AIDS orphans deal with psychological problems. When group members give and receive support and help from each other, this mutual aid empowers them to feel useful while learning to accept help and support from others (Garrett, 2004). With this support, group members may feel encouraged to deal with the stressors they experience in their communities.

#### 5.4.3.3 Macro Level

The *macro* level of intervention was also mentioned by most participants, who indicated that they work with communities where the children affected by HIV are coming from.

Networking with other organisations was mentioned as one way of intervention at the macro level.

*I am also networking on other organisations because we deal with referrals, so I keep in touch with them. (GU)*

*We also run consultative meetings or forums. It's more like all the partners within the community or within the district come together to tackle various issues or various topics or various things that relate to kids. (YB)*

*We have a child-care forum, do community dialogues, and NGO's get to gather and discuss specifics areas of service delivery. (SW 2)*

These findings indicate that collaboration amongst the existing organisations in different sectors working with CABHA and with the communities where interventions are implemented is key to the running of successful interventions. Organisations need to collaborate with organisations in different service delivery sectors to ensure holistic service delivery. Tumwesige et al. (2021) support collaborations with communities and argue that creating and sustaining community collaborations and partnerships are especially critical when implementing interventions. The HIV and AIDS orphan epidemic appears to be the responsibility of those at a community level (Breckenridge et al., 2019). Therefore, it makes sense that those planning interventions should collaborate with community members.

## 5.5 DISCUSSION

This study aimed to explore the current interventions provided to CABHA by service providers and the experiences of social workers in implementing interventions. Interventions aimed at CABHA must be well structured to ensure that they provide the correct and relevant services to those needing them. The initial stage of ensuring the relevance of the intervention is first to identify CABHA that need the services through assessment, referral and creating awareness in communities. The assessment is usually done by the person who comes into initial contact with the child in need of care. The results of this study indicate that regardless of the position of the person who identifies the need, most organisations follow the general guidelines as provided by the Children's Act 38 of 2005 that children in need of care must be referred to a designated social worker for investigation and intervention. The explanations given by the participants suggest that a needs assessment is done before deciding on the intervention. However, the fact that some of the initial assessments of CABHA are done by non-professional staff needs to be closely examined since there was no mention of how this process is monitored. Thurman et al. (2014) argue that caution should be exercised when using untrained staff when dealing with CABHA as they may not have the necessary skills to deal with complex issues that CABHA might bring. CABHA often face “developmental, psychosocial and economic adversities, less social support, fewer education opportunities, and higher risk for mental health challenges and risk-taking behaviours, compared to the general population: (Tumwesige et al., 2021:2). These issues require a person that is skilled enough to be able to deal with such problems. This means that organisations rendering interventions to CABHA need to ensure that those responsible for informal assessments of CABHA in need of intervention have adequate training and supervision provided to them on issues pertaining to CABHA.

Furthermore, these organisations must train their staff in all legislations concerning children and ensure that their programs align with the Children's Act 38 of 2005. This will ensure that when they identify CABHA children in need of care, they are directed to the correct intervention. Once the need for the services and intervention has been established, the organisation can decide how the intervention should be structured.

There is no universal way to conduct interventions aimed at CABHA, and each organisation structures interventions based on the needs identified. The gap, though, is that most organisations include CABHA as part of their service provision to OVC, which means that the specific needs of CABHA may be overlooked. This highlights a need for organisations to revisit their interventions to establish how to accommodate needs relating to HIV and AIDS vulnerability. Even though the child is the centre of the intervention, the beneficiaries often involve the caregivers/parents and other family members. It is also clear that the levels of intervention at the micro level can benefit the child as an individual. Still, there is also an added benefit in the mezzo level of intervention. In the mezzo level of intervention, the child often learns from those that have gone through similar experiences through support groups. Group members can learn that they are not alone in dealing with problems and can gain hope by observing others resolve their concerns (Popa, 2017). Previous studies have shown some benefits for CABHA who attend group sessions as they may feel supported by peers (Kumakech et al., 2009). Furthermore, Murphy et al. (2015) argue that there is a critical need to develop evidence-informed interventions that assist children in coping with parental HIV infection in a developmentally appropriate way.

Multisectoral collaboration amongst the organisations that work with CABHA is also key to the macro level of intervention. This indicates that it is important for organisations working with CABHA to liaise with one another to share their expertise. Collaboration with communities where interventions are implemented ensures that the interventions are adopted and supported by the communities where they are implemented. This is evident in the involvement of communities in marketing the interventions to the potential beneficiaries. Burke et al. (2015) concur that the inclusion of a variety of community-based organisations in the planning of a program helps develop interventions that are attractive to both community members and professionals who may deliver such programs. Social networks developed through group and community collaborative processes are important for building protective community environments (Tumwesige et al., 2021).

## **5.6 LIMITATIONS**

The recruitment process was challenging as government social workers could not participate in the study due to staff shortages and increasing work demands. This means that the focus of the study was mainly on NGOs and, therefore, restricted the participation of other social workers that might have been eligible for the study. The study findings are largely based on the NGO perspectives and are not transferrable to other research contexts. The sampling techniques used, purposive and snowball sampling, were limited as they depended on the researcher's ability to identify organisations that meet the selection criteria of the research and on the referrals made by other participants. The other limitation is a possible bias in the responses of some participants where interviews were conducted in groups, as some interviews had both superiors and subordinates in one group. Some participants may not have been able



to give a true reflection of their responses in a group setting due to the existing power relations of the different group members, thereby influencing the authenticity of the responses.

## **5.7 RECOMMENDATIONS**

The assessment and referral process of CABHA needs to be standardised as it is conducted by non-professional staff and volunteers who may not possess the necessary skills to conduct proper assessments of children in need of care. Social workers need to take the role of overseeing the supervision of staff the conduct assessments of CABHA.

Partnerships between service providers and communities need to be formalised to form community advisory boards that coordinate interventions for CABHA.

Organisations that provide interventions for OVC need to restructure their interventions so that the specific needs of CABHA are accommodated while also taking care not to create opportunities for discrimination against CABHA.

The input of CABHA needs to be requested and included in interventions as they need to have a say in what will work for them.

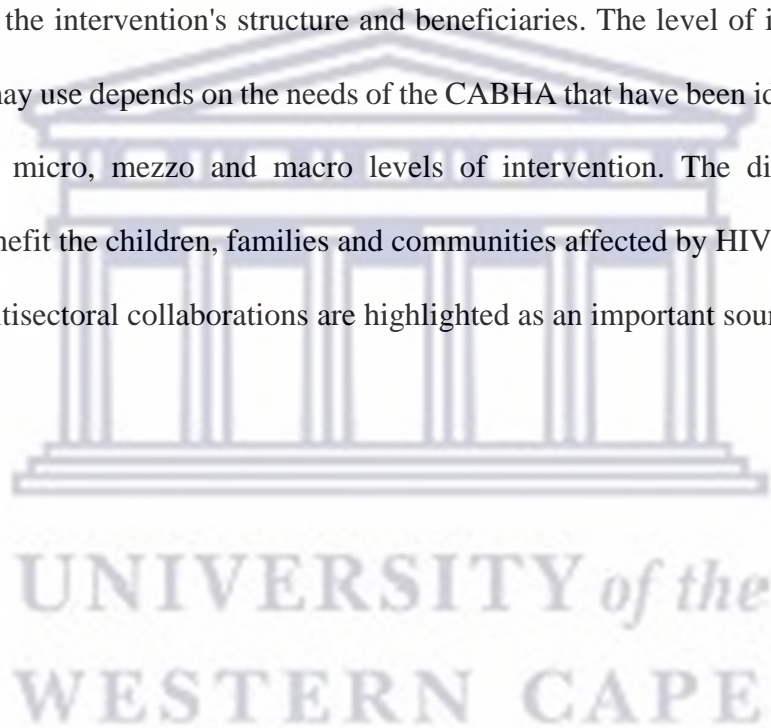
The organisations and stakeholders involved in the collaborations should work together with social workers and create referral forms that should be used by all non-professional staff when making referrals to CABHA so that there is consistency in these processes.

Organisations must provide regular training and capacitate volunteers and non-professionals with skills to develop their careers towards a qualification.

Future research should focus on evaluating the role of non-professionals and paraprofessionals in the implementation of interventions and how these categories of staff can be utilized optimally in the interventions for CABHA.

## **5.8 CONCLUSION**

The findings of this study indicate that interventions for CABHA are a continuous and collaborative process. Social workers must conduct a proper needs assessment before planning and conducting an intervention. A needs assessment involves identifying children needing care and deciding on the intervention's structure and beneficiaries. The level of interventions that social workers may use depends on the needs of the CABHA that have been identified and may decide to be at micro, mezzo and macro levels of intervention. The different levels of interventions benefit the children, families and communities affected by HIV and AIDS. Most importantly, multisectoral collaborations are highlighted as an important source of support for CABHA



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## **CHAPTER 6**

### **IMPLEMENTATION OF INTERVENTIONS FOR CHILDREN AFFECTED BY HIV AND AIDS IN THE CAPE TOWN METROPOLE: PERSPECTIVES FROM KEY ROLE PLAYERS**

This chapter describes reflections by key role players on the implementation of interventions for children affected by HIV and AIDS in the Cape Town metropole. The chapter is presented in the format of an article using the guidelines from the journal SAHARA-J: Journal of Social Aspects of HIV/AIDS, which is still under review. The chapter begins by giving background information, followed by a description of the research methodology and a presentation of the results. The chapter concludes with a discussion, conclusion and recommendations.

The logo of the University of the Western Cape, featuring a stylized classical building with six columns and a pediment.

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## **ABSTRACT**

HIV-related illness in parents often reduces their ability to care for their children, leaving children vulnerable to exploitation as they are left with no visible means of care and support. The vulnerability is exacerbated by the dire social circumstances that the children come from, which are dominated by poverty. These children are identified as needing care and thus require social work intervention. This study aimed to explore the implementation of interventions for CABHA and to describe the role players within these interventions with a specific focus on the social work role. The study was conducted using a qualitative research methodology through an exploratory design. Interviews were conducted with various organisations and social workers responsible for implementing interventions. Results show that most interventions focus on psycho-social support, community-based outreach, and educational, practical and parenting support. The key role players in interventions are a combination of professionals, paraprofessionals and volunteers. Social workers mostly take on the coordination role in the interventions. Paraprofessional staff are important in supporting the professional staff to implement interventions. This highlights the significance of working in interdisciplinary teams. The study also highlights the important role of paraprofessional staff and volunteers in implementing interventions, but there is no clear information on their training and monitoring. Practitioners responsible for the interventions are responsible for ensuring proper recruitment, training and monitoring of all role players responsible for implementing interventions.

**Keywords:** children, HIV and AIDS, intervention, parents, paraprofessionals, social work, support



## 6.1 INTRODUCTION

The impact of the HIV and AIDS diagnosis on individuals very often negatively affects everyone else in the family and brings the family functioning into a state of imbalance. When these HIV and AIDS-infected persons are also children's primary caregivers, this may negatively affect their parenting capacity. It is, therefore, important to understand the nature of these parenting challenges and know how best to deal with them (Sheer et al., 2016). Following the diagnosis, the roles of parents change from caregivers to those cared for because of illness which often leads to a reduced ability to care for others. Consequently, children are adversely affected due to parental absence, exacerbated by HIV-related illness and sometimes the parents' death due to HIV and AIDS.

The diagnosis of HIV and AIDS in the caregiver has been shown to have negative implications for the functioning of the child and harms the child's psychological well-being (Breckenridge et al., 2019; Nabunya et al., 2019; Schenck, 2009; Sheer et al., 2016; Tucker et al., 2016; Visser, 2015). Caregiving "ensures a safe and secure environment for young children and provides access to necessities such as food and shelter and stimulation and love to promote optimal development and protection from harm" (Sheer et al., 2016, p. 89). Therefore, those children affected and orphaned by HIV and AIDS are vulnerable as the illness and death of parents often leave them with no visible means of support. For the child, parental illness may trigger emotional distress and loss of freedom due to caring for an unwell loved one, disruptions to education, isolation, potential exploitation by family, and stigmas associated with AIDS orphan status (Tucker et al., 2016). It thus becomes imperative to understand the nature of the disruption in the lives of children affected by caregiver HIV before any interventions can be

implemented to ensure that those interventions cater for the needs of children affected by HIV and AIDS (CABHA). This is the reason that the term Orphaned and Vulnerable Children (OVC) is often used to describe these children who have lost a parent due to HIV and AIDS or those who are facing adverse social circumstances due to parental illness.

HIV and AIDS introduced an unprecedented challenge to families and communities throughout Sub-Saharan Africa, threatening the survival and development of children who have been orphaned and rendered vulnerable by individual, household or community circumstances Schenck (2009). This challenge is made worse by the dire social circumstances that the children come from, as these children very often live in communities that are overwhelmed by poverty. Breckenridge et al. (2019) confirm that orphaned children who live in poverty and have lost a parent due to HIV-related illness are more likely to have decreased coping mechanisms. The social, economic, and psychosocial impact of 'orphanhood' on children is intensified by the fact that many families live in communities already disadvantaged by poverty and limited access to basic services (Nabunya et al., 2019).

Strategies supporting orphaned and vulnerable children (OVC) are varied; they may include broad-based community-mobilisation initiatives or specific components such as planning for children's fostering and preventing land-grabbing through will-writing; providing psychosocial support; addressing poverty through income-generating activities; or fostering HIV prevention behaviours (Schenck, 2009). According to Schenck (2009), these strategies are usually the preferred method of intervention as opposed to residential care as they encourage less disruption in a child's life by keeping the child within their communities while encouraging community-based care and support. On the other hand, Li et al. (2014) argue that it is

appropriate to implement interventions at the family level that not only target HIV-affected children but also focus on the impact of the caregiver's HIV status on children's mental health.

Thus, there is no universal way of implementing interventions for CABHA and a 'one shoe fits all' approach will not work in the different contexts and communities where the children come from. There is, however, the consensus from the above statements (Li et al., 2014; Schenck, 2009) that interventions should focus on minimizing the disruption in the lives of CABHA and try to maintain a family system that will be able to provide a support network for these children. Interventions to reduce the incidence of orphanhood, which strengthens society's ability to support orphans, are essential, especially as the HIV epidemic matures and its full impact (Floyd et al., 2007). Sheer et al. (2016) further add that if children receive evidence-based interventions to maximize their potential, it is important to monitor children within a community setting and understand how community-based organisations (CBOs) are positioned as potential providers of support. This indicates that interventions aimed at CABHA should not only focus on the child as an individual but should include other systems in the child's environment that influence the child's functioning. Service providers, therefore, need to have clear guidelines for intervention to ensure efficiency in providing interventions to CABHA and their families.

To be able to provide guidelines for service providers on how to implement effective and efficient interventions for CABHA, it is imperative to examine the existing interventions to establish the best practice models and provide opportunities for proper program planning. This study aimed to explore the implementation of interventions for CABHA and to describe the role players within these interventions with a specific focus on the social work role.

## **6.2 METHODOLOGY**

### ***6.2.1 Study setting***

The study was conducted in organisations that work with children affected by HIV and AIDS. People who directly work in programs that provide interventions within these organisations and social workers that provide interventions to CABHA were included as part of the study at different stages of data collection. The locations of the organisations where participants were from were widespread across the Cape Town Metropolitan area. This area is situated in the Southern peninsula of the Western Cape province. These organisations service the Southern and Northern suburbs, Cape flats (including all the townships) and the greater Milnerton area up until Atlantis. This means that the interventions provided by the organisations cover communities of different cultural backgrounds and social statuses. Data collection in stage one took place within the different organisations at a time convenient to them as the organisations could not reach a consensus on a common date and time to meet at a venue that the researcher organised. Social workers were also interviewed in their chosen venues at a time convenient to them.

### ***6.2.2 Study design***

The study applied a qualitative research approach using an exploratory research design. A qualitative approach was deemed appropriate for this study since it aims at exploring and understanding the meaning individuals or groups ascribe to a social or human problem (Creswell & Creswell, 2018). This approach was regarded as the relevant approach to use since the study sought to investigate a topic that the participants could only describe based on their personal experiences. Permission to conduct the study and ethical clearance was granted by the

Department of Research Development of the University of the Western Cape (UWC), with an ethical clearance number of 15/6/30.

### ***6.2.3 Participants***

Participants of the study were employees of Non-Governmental Organisations (NGOs) that provided interventions to children affected by HIV and AIDS and were selected through purposive sampling. The purposive sampling method is based on the researcher's judgement of who will provide the best information to succeed in the objectives study (Etikan & Bala, 2017). The participants of stage one of the data collection required people employed by the organisations mentioned above but had to be directly involved in implementing the intervention. The selection criteria were that 1) the organisation to be implementing HIV and AIDS-related psychosocial intervention programs; 2) be a Non-Governmental Organisation (NGO), Community Based or Church based Organisations (CBO), Non-Profit Organisation (NPO) or government department; 3) interventions programs to be aimed at CABHA; 4) organisations to have a designated person/s able to explain about the programs. These participants did not have to be in a specific profession. The organisation identified them as the best persons who would be able to describe the interventions due to their direct involvement in the implementation of the interventions. These participants occupied different positions with the organisations. In stage two, the focus was on social workers working in organisations that provide services to CABHA and these social workers were identified through a snowball sampling method. Snowball sampling involves “approaching a single respondent or case that can provide rich data pertaining to the phenomenon being investigated, and this person is requested to refer the researcher to other with similar experiences” (Strydom, 2021, p. 383).



Participants were asked to identify social workers who work with CABHA and refer the those social workers. Each social worker subsequently interviewed was then asked to refer to another social worker who would then be approached for participation in the study. This process continued until no new social workers were mentioned or the same names were mentioned. The final number of participants that participated in the study was 28. A summary of the participants' demographic details is outlined in table 6.1.

**Table 6.1 Demographic Profile of Participants**

<b>Characteristic</b>	<b>N</b>	<b>%</b>
Program coordinator	3	<b>10.7</b>
Social worker	18	<b>64.2</b>
Professional nurse	2	<b>7.1</b>
Counsellor	1	<b>3.5</b>
Director	1	<b>3.5</b>
Youth counsellors	2	<b>7.1</b>
Youth Worker	1	<b>3.5</b>
	<b>28</b>	

#### **6.2.4 Data Collection**

Invitations to participants for the study were sent to managers of various organisations via email requesting access to participants that meet the selection criteria. The organisations that agreed to participate forwarded the invitation to those staff members that met the selection criteria and gave permission for the researcher to contact the participants. The participants were contacted, the research process explained to them and were given the opportunity to voluntarily participate in the interviews. The data was collected through semi-structured interviews using an interview guide. With semi-structured interviews, “the researcher enters with a firm overview of the relevant literature and having prepared numerous open questions to be asked” (Ellis, 2016, p. 104). Using semi-structured interviews, means that the interviews were

conducted with a set of prepared questions to guide the direction of the interview. The interview guide used had open-ended questions linked to the study's aim, which had three focus areas. The focus areas required participants to describe the types of interventions provided to CABHA, identify people that play an active role in the implementation of the interventions and explain the role of the social worker in the interventions. Participants were assured that the information shared would be kept confidential and were made aware of their right to withdraw from the study at any given point in time. The option of counselling by a registered social worker was offered to participants if they needed it after participating in the study, but none of them felt the need to use it. Interviews took place in venues chosen by the participants, which was their place of employment in all the instances, and the interviews lasted between 60 to 90 minutes. All the interviews were conducted in English as all the participants were comfortable conversing in English.

#### **6.2.5 Data analysis**

Once data was collected, it was analysed using thematic analysis. Thematic analysis requires the researcher to “systematically work through qualitative data to identify common threads of meaning, to group these together into categories of meaning and to then cluster these into higher-order themes” (Willig, 2013, p. 58). This means that the data was taken through a step-by-step process and analysed to produce common themes that emerged from the participant's responses. This process involved multiple layers of analysis, and the researcher specifically followed five steps of data analysis as suggested by Creswell and Creswell (2018). These steps involve organising, reading, coding the data and ultimately generating themes that are presented in a qualitative narrative.

## 6.3 RESULTS

The participants described a variety of interventions provided by different service providers in organisations who render interventions for CABHA, as well as the role players involved in these interventions. The description of interventions provided by the participants specifically focused on the types of interventions, the role of the social worker and the other role players in the interventions for CABHA.

### 6.3.1 Types of intervention

Although the service providers gave different accounts of the types of interventions that they do, all the interventions that were described come down to five major categories: psycho-social support; community-based outreach; education; practical and parenting support.

#### 6.3.1.1 Psycho-social support

Psycho-social support proved to be one of the popular focus areas of intervention. This includes counselling, life skills programs and skills development. These services are provided and facilitated by different categories of staff in each organisation which will be discussed in detail later in the chapter.

The social workers mostly mentioned counselling as one type of intervention that they use. The social workers mentioned that they provide individual counselling for the child and sometimes include the family. Furthermore, some social workers highlighted grief counselling as one of the issues that the counselling sessions focus on. These were the responses of the participants:

*I provide counselling for the child. (SW 2)*

*I do individual counselling for children and also some families. (SW 6)*

*When the parent dies, that part is the grieving part of the child, I don't label them by the fact that their parents died of HIV, and I prefer using a less stigmatic method. (SW7)*

Most of the responses highlight that counselling is primarily provided to children. However, some of the participants reported that counselling is also provided to the parents or caregivers, as reflected in the following quotes:

*Social workers provide them with counselling, give them (parents) practical support, advise them about grants. (SW 5)*

*To me you need experience working on HIV cases to know the right time to tell, empower and educate the grandparents who many also be struggling with the idea why the mother died, social workers have to do all that. (SW 8)*

The participants added that over and above the counselling provided to the children and their families, additional psychosocial support interventions such as life skills programs are provided to CABHA. The target group of each life skills program differed according to the needs identified by the organisation.

*It's focusing on life skills basically cos people who are facilitating the group are facilitators, they are not social workers. (AT)*

*It's focusing on life skills... In our first session we look at, we look at human foundation, the circle of courage. Then we go to choices, feelings, consequences, developmental stages. (GU)*

*The life skills educators go to their homes and then find, and then they refer them to the OVC programme. (LH)*

### 6.3.1.2 Community-based outreach

The participants also mentioned another popular focus area, community-based outreach that focuses on healthcare, networking and stigma prevention. One of the healthcare services that was reported to be provided is HIV Counselling and Testing (HCT). Participants explained that they use home visits as a means for follow-up of HCT clients and to encourage HIV testing of partners. A participant mentioned that

*If they can't come to the facility then we can go out to them and then the partner can also be tested. (LH)*

*Sometimes it is very far to go to the clinic, and we decide to call the mobile clinic so that the clinic can come nearby so they can access it close by. So, the clinic will come, and we will invite them to come and do the tests at the centre. (YB).*

Home visits provide the opportunity for CABHA and their families to have access to needed resources closer to their communities. These responses indicate that healthcare services are not limited to a clinical setting or building such as clinics. Still, they are community-based to ensure that the services are brought closer to the people in the communities.

Furthermore, some organisations highlighted the importance of networking with local healthcare facilities to monitor and refer clients needing urgent medical attention. The interaction between stakeholders involved with interventions for CABHA was highlighted as an important thing to do. Networking with other organisations regarding the provision of healthcare services to the community was mentioned as an important part of community-based outreach. Participants explained that:



*We have stakeholder meetings every month, to keep updated every month. Clinics, NGOs, the police and SASSA. It helps us refer so we know the contacts to refer to, we have each other's contacts. (AT)*

*We are working well with clinics, we're working well with schools, we are connected with other organisations in our communities. (O2)*

*We have meetings that we attend, which is a collective of organisations and they do meetings every two months and discuss as the organisations of the area. We meet and get to know new persons delivering services that we don't have. (SW 6)*

Another important issue from participants being addressed through community-based outreach is preventing HIV-related stigma. The participants mentioned that the organisations provide supportive services in the communities which aim to tackle HIV-related stigma.

*We also tackle stigma, awareness, and some outreach programs in partnership with other organisations. We have winter programs where we collaborate and focus on a specific topic, and we arrive on one goal. (GU)*

*There is fear attached to HIV and AIDS, they meet other children that are HIV positive, they understand that they are not alone in this, it's not the end of the world if you're HIV positive. (SW 2)*

#### *6.3.1.3 Educational support*

Education was clearly the most popular focus area of intervention, as all the participants mentioned it as one of the focus areas of their interventions. Participants mentioned different educational programs offered by the organisations that focus on early childhood development

and academic support. Some participants reported that as part of their intervention, they have an early childhood development centre and youth programs on their premises, while others mentioned developmental assessment:

*In our centre we have early childhood development for children. So, we have children from 3 years up to 6 years, where we have grade R and then we have child and youth programmes. (AT)*

*Our educational person can see that something isn't right, take the child to OT and let's try and assist and develop that child so that they can better their performance in school as well. (H4H)*

These responses indicate that the organisations use various approaches to help with children's developmental needs. This ranges from developmental assessment for early identification of problems done by an occupational therapist to the placement of children in schools suitable for the child, all aiming to assist children in coping well with their learning needs.

Some organisations reported academic support as part of their educational programs. The reason for providing tutoring to CABHA was not clearly explained, except that it was to give extra academic support and a space for the children to work on their schoolwork.

A participant reported that they provide academic support to children through tutoring:

*We get tutors to go out into the houses and do the tutoring with the children and then we build a relationship with external can you call them stakeholders. (GU)*

Another participant also reported that they assist children with homework by providing their premises as a resource centre.

*After school children must come here to the centre for three days, ...we help them with homework others have assignments they need to do, and they need internet. (UWL)*

#### *6.3.1.4 Practical support*

The least popular type of intervention identified in the organisations proved to be practical support. The types of practical support reported are food security, financial assistance and skills development. Even with limited funding, UWL highlighted that they assist with transport fares for the children. A participant said:

*We give them money for a taxi home. When they finish after five the teacher will help them get the taxis that will get them home safely. (UWL)*

Another type of practical support reported relates to skills development facilitated by the organisations, and these are aimed at parents and older CABHA. These interventions aim to empower the communities and parents of CABHA with skills that will assist them in getting some form of financial freedom. The following responses reflect this type of skills development:

*We had some beading because we trained some 100 people for beading skills. So that they can be able to sell them for themselves. (SW1)*

*There's a way to work if there's unemployment, they can come to the job centre and here at the job centre they equip them and they skill them how to do a CV, and how to look for jobs, how to acquire job and how to stay in the job as well. (LH)*

These findings above show that the organisations work not only with children but also with parents and caregivers for the benefit of the children. Furthermore, the findings also revealed

that the organisations take practical support a step further by offering parenting skills programs.

#### 6.3.1.5 Parenting support

As mentioned in the previous section, although the focus is on children, the organisations also involve parents and caregivers in parenting skills workshops to benefit their children and families. Participants reflected that:

*Through our parenting workshops we have reached many parents because we have a target of 200 parents. (SW1)*

*We also have programs that enlighten and empower parents as to how to deal with their kids...more especially the teenagers, more like strengthening the relationship between kids and parents. (NCS)*

*It's a nice time for them to get together and get to share experiences and what works and does not work for them. (H4H)*

The workshops do not only focus on HIV and AIDS-related topics but also include other issues that relate to general parenting. A participant also reported that they have a 'fatherhood' workshop where they train 40 fathers on parenting skills. The provision of a parenting workshop that includes fathers indicates that the workshops are inclusive and that there is no discrimination based on gender.

Some organisations take a slightly different approach to parenting support, as their focus is child protection and care. They specifically focus on the recruitment, screening and monitoring of potential foster care parents. The screening is done by doing a background check on parents and conducting foster care training workshops where they provide

information on foster parenting and provide support to potential foster parents. They mentioned that:

*We recruit potential foster parents through the local media, religious organisations and community meetings. All the social workers that are doing placements can contact us because we have a database of foster parents that are trained, we have done the background. (UWL)*

*We also do 'fostering' where we also do parenting skills training, home assessments, training and referral of foster parents. (SW 5)*

*We are cluster foster care scheme organisation and we're basically also a child protection organisation. We work closely with the department of social development with regards to this and provide a safe home and environment and family to orphans and vulnerable children. (SW 7)*

The participants' responses show that the organisations provide supportive services to social workers in ensuring that suitable foster parents are found, trained and made accessible to social workers when placement of a child is needed. These findings indicate that the organisations have a very important role in the placement of foster children and that they work closely with those social workers with the statutory power to facilitate formal placements of children in foster care. They all work together to ensure that the child's best interests are protected and maintained.

### **6.3.2 Role-players in the implementation of interventions**

The results indicate that most organisations use a multi-disciplinary and inter-sectoral approach in their service delivery. Several role players are involved in delivering services to CABHA,



and these consist of staff members of various categories. The staff categories include social workers, other professionals (health and social service), paraprofessional staff and volunteers. The roles of each of the different stakeholders will be described further below.

#### 6.3.2.1 Social workers

Most organisations mentioned that social workers complement those who perform various roles and responsibilities closely related to the social work profession. The most common roles and responsibilities reported related to case manager/coordinator, supervisor and administrator. In terms of the coordinator role, the participants explained the role of a social worker in the following manner:

*I also manage support services. (SW 1)*

*I am the OVC manager, meaning that I oversee many issues like psychosocial problems. (SW 2)*

*To integrate the whole bits and pieces of the programme because this one now is just focused on home-based care, although they do refer back. (LH)*

The participants' explanations indicate that social workers occupied the title of a program coordinator, where they oversee the running of programs in the organisations. These descriptions clearly indicate that the social worker's role is to lead the process of intervention by bringing together the different services required by clients to ensure that the needs of clients are met.

The other common social work role reported by the participants relates to supervision. Supervision of staff members was also identified as one of the key roles of social workers.

*The social worker would intervene on the staff matters as well because we as staff also need emotional support, other instances she offers educational support, so she becomes handy to us. (YB)*

*I do some debriefing for my team, even if we know that day, I will find something, we do send questions about their lives, team building exercise. (SW 1)*

*The role of a social worker would be to supervise, to make sure that those interventions are implemented. (SW 5)*

Several participants mostly describe the supportive role of the social worker as a supervisor. The explanations focus on the emotional support provided by the social work supervisor. They emphasise that the social worker monitors the work done by other staff members and provides opportunities for staff to debrief about their work. This shows that the social worker provides emotional support to the staff through the debriefing sessions.

The other type of social work role directly linked to the role of a case manager is administration. The participants mentioned that the social worker is responsible for signing off documents relating to orders of material things for the organisation and recruiting staff.

*Even if I am not here, they make the order and I see if the code is right and I sign it off. They just send it to me. (SW1)*

*I am head of PR and liaison office, and I also deal with recruitment of stakeholders as well. (GU)*

The descriptions of the social worker's administrative function relate to the organisation's day-to-day running. This is where the social worker must ensure that all paperwork pertaining

to the organisation's management is in order. In some cases, this also includes accountability to funders, as mentioned by SW 2, who reported that:

*I monitor and supervise programmes and see if it works or not, to report to our funders.*

The explanations given by the participants indicate that social workers have an important administrative role to play in ensuring the efficient operation of organisations.

#### *6.3.2.2 Paraprofessional staff*

In addition to social workers, different types of professionals were mentioned as critical role players who work hand in hand with the social workers. These are nurses, community health workers (CHW), community workers, caregivers, social auxiliary workers (SAW), child and youth care workers (CYCC) and community development practitioners (CDP). Nurses were also highlighted as the other professionals associated with the organisations as they attended to the client's medical needs as part of the interventions. LH identified a testing team in the intervention, which consists of a nursing sister and the two councillors that community health workers support. Due to the high numbers of clients and the countless communities served by the organisations, paraprofessional staff such as community health workers and CYCCs were identified as a support service that the organisations use to assist with the medical needs of clients:

*They (community health workers) can do dressings; they can do medication and they can do follow up of patients. (LH)*

*Based on the need the organisation will send two community workers for training so they will be able to do this (HIV) testing. Which you don't do as an organisation but in partnership with others. (UWL)*

*Child and youth care workers manage the medication and the clinic visits. (SW 6)*

When explanations were given about their roles, the distinction between community health workers and community workers was not clearly made. Community workers do more of the general work, while community health workers focus on health-related matters. SAWs and CYCCs were also identified as the family support workers working with the social workers.

*Social auxiliary workers, child and youth care workers – we call them family support workers – we call them family support workers. (LH)*

*The social worker has support from the community workers, with the visits the community workers do them and report to the social worker. (UWL)*

*They (caregivers) are the ones who identify the needs in the community then report to you then you refer to the family strengthening officer and then the whole process continues. (AT)*

SAWs and CYCCs were reported to be responsible for conducting home visits and parenting workshops in a role that supports social workers. Caregivers were also identified as the ones that conduct home visits to assess the child's social circumstances and referral to the social worker. It became evident that organisations use the different categories of staff similarly in the interventions, but the choice of who does what depends on the structure of the team within the organisation. Some organisations use caregivers who do home visits where they assess the home circumstances, which they report to the social worker, especially the difficult cases or cases they are not trained to deal with.

### 6.3.2.3 *Volunteers and other trained staff*

Some organisations mentioned that they make use of volunteers in their service delivery.

*If we have someone from the community who can positively influence our kids, we use them to come and teach them things like craft, arts, so we basically, empowering them.*

*(YB)*

Additionally, another participant mentioned that they make use of volunteers who are referred to as community mothers and assistants and that

*Each community mother has 25 children, and then an assistant, so they cook for them, they have a meal that they get when they get back from school. (SW 2)*

As a precaution, a participant from YB mentioned that when they feel the issue is beyond their scope of work or expertise, they refer to qualified professionals, such as the social worker, for further intervention. This shows that sometimes volunteers can end up with a workload that is not part of their scope. Working closely with the professional staff allows them to refer such cases.

## **6.4 DISCUSSION**

Results show that two important elements make up interventions for CABHA and these relate to the types of interventions and the key role players. The types of interventions the organisations provide are structured according to the client's needs. All the organisations indicated different types of support, such as psycho-social, community-based outreach, educational, practical and parenting support. The key role players in implementing



interventions consist of professionals, paraprofessionals and volunteers who occupy various positions and perform different tasks.

#### ***6.4.1 Types of interventions***

##### *6.4.1.1 Psychosocial support*

Psychosocial support can be provided by counselling CABHA and their families and teaching them life skills. These children are often affected negatively by the illness and sometimes the death of a caregiver due to HIV-related illnesses. Caregiving ensures a safe and secure environment for young children. It provides access to necessities such as food, shelter, stimulation, and love to promote optimal development and protection from harm (Sheer et al., 2016). A South African study of children orphaned by HIV and AIDS (Breckenridge et al., 2019) revealed that the OVC illustrated high rates of grief and loss associated with the death of his or her parent(s).

Previous studies have shown that the children affected and orphaned because of HIV and AIDS are often vulnerable as the illness and death of parents results in loss of emotional, financial and material support (Breckenridge et al., 2019; Nabunya et al., 2019; Schenck, 2009; Sheer et al., 2016; Tucker et al., 2016; Visser, 2015). Furthermore, orphaned children in South Africa are generally cared for by extended family members following the death of their parent/s or when the whereabouts of their remaining parents are unknown (Breckenridge et al., 2019). Therefore, the children's primary source of support decreases in the absence of parents, and they may require intervention to assist them cope with the new reality of being orphans or having to deal with a sick caregiver. Parental illness may also trigger emotional distress for the child and loss of freedoms due to caring for an unwell loved one, as well as disruptions to

education, isolation, potential exploitation by family, and stigma associated with AIDS orphan status (Tucker et al., 2016).

This is where the need for counselling comes in, as it is meant to provide clients a space and opportunity to deal with the loss they are experiencing to return to their normal level of functioning. Caution should, however, be exercised when assessing the level of psychological functioning and emotional distress of children who have suffered loss, as the experiences of loss may differ across cultural contexts. Therefore, Betancourt et al. (2011) emphasise the importance of understanding local manifestations of mental health problems when conducting mental health assessments and planning interventions for HIV/AIDS-affected children in diverse settings.

It is also important to note that attending to the child's emotional well-being might not be effective psychosocial support if only done to the child alone, as there is often a need to include other family members in the intervention. Psychosocial support should be visible before the caregiver becomes ill or dies from HIV-related illnesses. Sheer et al. (2016) highlight the importance of interventions directed at alleviating parental depression in the presence of HIV and that these may help to interrupt the cycle of family HIV and adverse child outcomes. This means that interventions should also aim at addressing parents' psychological problems that may be linked to the HIV diagnosis, as these may ultimately affect the child if it not addressed.

Furthermore, as part of psychosocial support, the results showed that interventions teach CABHA life skills meant to address their physical, educational and psychological needs.

Previous South African studies (Bhana et al., 2014; Boon et al., 2009; Visser et al., 2015) identified life skills programs as common intervention methods used by different service providers to address the physical, educational and psychosocial needs of OVC. These life skills programs had different focus areas depending on the needs identified in the OVC, and most of them were reported to positively impact the lives of the OVC. However, caution should be exercised when referring to common practices as these often differ according to the context of the communities where they are implemented. Life skills programs, therefore, should be tailored to fit the culture and context of the communities.

#### *6.4.1.2 Community-based outreach*

The organisations also offer interventions that focus on community-based outreach to promote the physical and psychosocial well-being of CABHA. These community-based outreach programs are implemented in different ways, including healthcare services that are implemented through home visiting and mobile clinics. These strategies ensure that the services are brought closer to the people in the communities, which may increase health-seeking behaviours. This is in line with the findings by Tomlinson et al. (2016), who also identify the use of mobile health units as a response to deficiencies in healthcare infrastructure, particularly in remote rural areas in Africa, to address the service access gap to serve the needs of remote communities. In contrast, home visits may have some benefits, such as bringing services closer to the people and in the comfort of their own homes, Thurman et al. (2014) caution that no evidence exists that measures the effectiveness of this method. This highlights a need for interventions that are evaluated regularly to ensure that these home visits provide some benefit to CABHA.

Previous studies (Kidman et al., 2014; Thurman et al., 2014) identified home visiting as a common mechanism for providing basic counselling, healthcare and other services to HIV-affected families. On the contrary, Thurman et al. (2014) warn that home visits may not always be effective even though they may be a common practice. As much as the use of home visitors is a common method of service delivery, a question should be raised on whether this results in a measurable gain for the people to whom the service is directed. Conceivably, the emphasis should be on the content and aim of the home visit rather than on the activity of home visiting. There is, however, some benefit linked to home visiting. Betancourt et al. (2014) recommend home visiting that is linked to Family Strengthening Intervention (FST) and argue that the home-visiting nature of the intervention enhances access by allowing counsellors to reach many vulnerable children at once and decreases barriers related to accessing healthcare or psychosocial interventions for children and families affected by HIV and AIDS. The services provided through home visits should focus on strengthening the whole family and not just the individuals. This shows the importance of empowering families to confront HIV-related challenges and the need to develop child-adequate and age-specific intervention strategies (Li et al., 2014).

Networking amongst organisations providing services to CABHA was also reported to be a strategy that most organisations engage in. Networking to establish strong community and institutional partnerships is emphasised as important in ensuring community outreach efforts are supported by communities (Bhana et al., 2010; Breckenridge et al., 2019). The direct involvement of the community in the interventions meant for CABHA may also help in the eradication of HIV-related stigma and discrimination that exists in the communities. Aggleton

et al. (2005) argue that HIV-related stigma can lead to discrimination and other human rights violations, which affect the well-being of people living with HIV in fundamental ways. A recent global AIDS report by UNAIDS (2020) highlighted that stigma discourages people from seeking health services. This confirms why it becomes important for organisations to work together towards eradicating HIV-related stigma in their interventions.

#### *6.4.1.3 Educational support*

Early childhood development is provided as a form of educational support to CABHA to assist with assessing and identifying potential developmental problems. There is limited research that specifically refers to the link between early childhood development and HIV. A study by Tomlinson et al. (2016) identified children affected by HIV/AIDS as at serious risk of developmental delays. The reason for this is probably because children who grow up without both or either of their parents due to HIV illness or death face countless challenges which often interfere with their schooling and, at times, result in them falling behind academically or even leaving school (Breckenridge et al., 2019; Chitiyo et al., 2008). The absence of a caregiver may add to their emotional instability and the lack of academic support, thereby leading to poor performance at school. In some instances, parents may be too sick to be able to take proper care of their children's educational needs. Therefore, the interventions that focus on early childhood development are likely to assist and ease the burden for the parents by placing the children in appropriate ECD centres and encouraging early identification of developmental problems.

Academic support programs offered by the organisations through tutoring and after-school care are meant to provide a safe space for CABHA to perform their academic duties. School



attendance in CABHA has been shown in previous research to be negatively affected by the caregiver and household HIV (Sherr et al., 2016). Academic support programs have the potential to promote school attendance and school connectedness amongst CABHA. School connectedness is described by the Centers for Disease Control and Prevention (2009) as “the belief by students that the adults in the school care about their learning as well as about them as individuals”. This is an issue that was identified by Sharp et al. (2018) as important for OVC because social and psychological connectedness to school is an important resilience factor for youth affected by adversity. This means that it is important for youth to feel confident in their school environment and feel that the environment is accommodating towards them for them to thrive. The academic support offered by the organisations provides an opportunity for the CABHA to feel that there are adults who care about them and their learning, even though this is not in the school environment. Hopefully, this will encourage school connectedness in the CABHA, ultimately promoting school attendance.

#### *6.4.1.4 Practical Support*

Social grants, skills development and job creation initiatives were identified as practical support provided to families of CABHA. Ssewamala et al. (2016) identify household economic instability and poverty as hardships for children orphaned due to HIV and AIDS experience. The South African government provides social security specifically aimed at children through Foster Care Grant (FCG) and Child Support Grants (CSG), dispersed to caregivers to alleviate some of the economic difficulties associated with raising orphaned children. Breckenridge et al. (2019) argue that despite these limited funds, poverty remains a serious factor that affects orphaned children not only after a parent’s death but also before the death of a parent. It is clear

that these families still need the practical support provided by the organisations because of their poor financial status, which could be due to receiving no social grants or insufficient grant money. Ssewamala et al. (2016) argue that when a parent falls ill due to HIV and AIDS in a resource-constrained household, money meant to cover children's needs may be diverted from education to cover other needs like medical costs. This means that the family may be left in a difficult financial position with no funds to cater to other family members' needs. The practical support provided by the organisations is there to assist the families in bridging the gap in their financial status.

Providing financial assistance to families of CABHA may, however, not always be the best solution. There is no guarantee that the money received will be used to the benefit of CABHA. Karimli et al. (2019) suggest that interventions should focus on reducing poverty's impact on CABHA than providing income. The skills development could work if the direct beneficiaries are the older children, as this would assist them in the future regarding job opportunities. However, there may be a potential unemployment problem after leaving the program due to a lack of job opportunities in the communities of CABHA. Visser et al. (2015) warn that despite these initiatives, scarcity of employment and livelihood opportunities, particularly in rural areas, jeopardises OVC's future and may lead to new vulnerabilities. However, innovative family-level economic strengthening programs may have positive developmental impacts related to education, health, and psychosocial functioning on children orphaned by HIV and AIDS (Han et al., 2013; Ssewamala et al., 2016). Caution should, however, be exercised with economic strengthening programs as they may not be the ultimate solution to poverty alleviation in the families of CABHA.

Organisations need to collaborate with future employers and work on programmes that focus on job creation. Equipping CABHA with job-seeking skills becomes pointless when no jobs are available. Perhaps lessons need to be learned from one organisation that teaches parents to be self-sustaining through beading. An evaluation needs to be done to establish if the skills learned through this project lead to economic stability for the families involved. Furthermore, there is a need to ensure more involvement of community members in the screening processes of the beneficiaries of these interventions so that the whole community benefits. Previous successful programs (Goodman et al., 2014) that focused on the economic empowerment of families of CABHA formed community partnerships and community stakeholders, village chiefs, and religious leaders conducted the initial screening for program inclusion. This method needs to be adapted by those providing interventions to ensure buy-in and support from the leaders in the communities where interventions are implemented.

#### *6.4.1.5 Parenting support*

The content of the parenting skills workshops differs according to the needs identified by each organisation. There are various topics covered in the parenting workshops ranging from educating parents on living with HIV and AIDS, disclosure, fatherhood and general parenting issues. Cable (2017) argues that South African fathers are generally stereotyped as either absent, authoritative and not playing an active role in their children's lives, which has given rise to the ideology that fathers are unable to construct nurturing and caregiving roles normally associated with the mother's role. The fatherhood workshops are meant to curtail these stereotypes and include fathers as active parents. A few types of parenting interventions were evaluated in previous studies (Bhana et al., 2010; Boon et al., 2009), which focused on

improving the skills and AIDS knowledge of caregivers of CABHA. The results showed that caregivers had greater comfort in talking about sensitive issues with their children and increased monitoring of their children after attending these interventions (Bhana et al., 2010; Boon et al., 2009).

Regarding foster care placements, the results show that all the organisations work together to ensure that the child's rights are protected. Section 56 (1)(e)(i) of the Children's Act 38 of 2005 states that 'if a children's court finds that a child requires care and protection the court may make any order which is in the best interests of the child, which may be or include an order if the child has no parent or caregiver or has a parent or caregiver but that person is unable or unsuitable to care for the child, that the child is placed in foster care with a suitable foster parent'. It is the duty of the social worker to identify these children in need of care and ensure that they are placed with appropriate caregivers. There are clear guidelines from the South African government regarding who is considered a suitable foster parent. Only a person screened and found fit and proper can be approved as a foster parent by a designated social worker from the Department of Social Development or a designated child protection organisation that undergoes training can foster a child (Western Cape Government, 2021). The organisation's foster care training and assessment is the very important groundwork to ensure that the foster parents are suitable to foster children. Once again, the collaboration between government and NGO social workers plays a very important role.

#### ***6.4.2 Role Players***

Depending on the needs identified, the people responsible for implementing the interventions are different people within the organisations. The findings indicate that social workers take

on the role of coordinators and supervisors within the interventions. This role is responsible for overseeing the overall running of the intervention and supporting other staff members. Coordinators of the programs occupy positions where they are responsible for managing the interventions and ensuring consistency, accountability and implementation. The descriptions given by the participants are a combination of the social work role of a case manager and coordinator. A case manager is a practitioner who assumes primary responsibility for assessing a client's needs and arranging and coordinating the delivery of essential goods provided by other resources and services on behalf of a specific client (Hepworth et al., 2010). Kirst-Ashman (2017) describes a coordinator as coordinating people by bringing them together and organising their performance. Both these definitions describe exactly what the participants explained about the social worker's role in managing and coordinating the interventions.

The supervisor role of the social worker is also closely linked to the roles mentioned above but focuses more on the monitoring and support of staff. Supervision is “a working relationship between an experienced and an inexperienced worker, during which guidance is given by the experienced worker to improve the knowledge and enhance the abilities of the inexperienced worker” (Nicholas et al., 2015, p. 147). The supervisor also provides emotional and educational support to the staff, which may enhance their abilities in the long run. The emotional support provided to the staff members is done as a form of debriefing meant to assist them in dealing with the stress they experience in doing their jobs. Nicholas et al. (2015) agree that the type of stress and burnout inherent in many organisations often warrants debriefing sessions with the social work manager. The findings also indicate that social



workers guide other staff members through training and monitoring the work done. However, there was no mention of the supervision's structure and frequency, which is a very important aspect of supervision. This raises concern about whether the supervision that is mentioned is formal.

SAWs and CYCCs are required to be registered with the South African Council for Social Service Professions (SACSSP). UWL also provides a similar service to home visits which the community workers do. AT also mentioned having. The paraprofessional staff have an important role in supporting the professional staff. Mwai et al. (2013) argue that CHWs must be recognised, remunerated and integrated into wider health systems. This is supported by Kidman et al. (2014), who contend that programs that invest in compensation and extensive training for home visitors can better serve and retain beneficiaries. However, there is no evidence that investment in paraprofessional services results in higher-quality service delivery.

The role of para-professional staff, such as community health workers, and social auxiliary workers, that are linked to these interventions is worthy of being noted as it is quite a significant role. Kidman et al. (2014) argue that many programs have created a paraprofessional workforce in response to the high demand for intervention. Previous studies (Hermann et al., 2009; Mwai et al., 2013) identified community health workers as an essential part of community-based health services as they deliver a high standard of care and strengthen service delivery in primary healthcare. However, Thurman et al. (2014) caution that relying too much on these paraprofessionals poses a challenge of limited counselling skills, which may prevent them from properly dealing with the psychological needs of clients.

Additionally, some organisations use volunteers, which becomes very helpful in day-to-day interventions where practical help is needed in daily activities where extra hands are needed. However, volunteers should be properly screened and trained before involvement in the interventions. Organisations also need to ensure some form of compensation for the volunteers or clarify where there will be none to avoid confusion about remuneration. Previous studies have shown that inadequately trained and poorly compensated volunteers result in poor program quality (Lehmann & Sanders, 2007; Schenk & Michaelis, 2010).

Furthermore, Organisations should discuss with volunteers before they commence any work to ensure that there is an agreement on the expectations and clarify if there is compensation for volunteers. Regular monitoring and evaluation of volunteers during the intervention is important in ensuring that they fulfil their expected roles and that the goals of the intervention are met. Furthermore, networking amongst organisations is a crucial part of implementing interventions.

## **6.5 LIMITATIONS**

Most of the limitations of this study relate to the methodology used. The sampling techniques used in both data collection stages limited the number of people that could participate. The selection criteria relied on other people to identify participants that meet the criteria. There is a possibility that key participants may have been missed and not participated in the study since the participants were received via contact persons in the organisations or referrals by other participants. Furthermore, the population used to sample organisations working with CABHA was small since there was little information available on organisations rendering services to CABHA. This means that the results may not be generalised to all organisations.

However, the referrals for organisations reached data saturation as the same names of organisations kept coming up when further referrals were asked for. Perhaps, the limitation is that the results may only apply to an organisation in the Cape Town Metropole and not necessarily the rest of the Western Cape or South Africa. The selection criteria referred to CABHA and omitted OVCs as it became apparent during data collection that CABHA is very often integrated into services for OVCs. This means that some organisations that render services to CABHA and contain critical information about CABHA were missed since their focus is on OVCs.

## **6.6 CONCLUSION AND RECOMMENDATIONS**

The diagnosis of HIV and AIDS in the parent/s has been shown to affect the child's functioning negatively. Parents' ability to take care of the children is minimised because of HIV-related illness, and CABHA faces multiple risks to their well-being. The types of interventions provided to CABHA need to focus on different levels of support: psychosocial support, community-based outreach; education; practical support and parenting support. This study and previous research have shown that the chances of these successful interventions are increased when there are partnerships with the communities and other stakeholders that work within these communities. Social workers have an important role to play in the facilitation of these interventions, where they take on the role of case manager and case manager in bringing the needed resources together to work for the benefit of the CABHA, families and the community. Paraprofessionals and volunteers are also vital in these interventions as they work closely within the communities, build relationships with them and act as a link between organisations and CABHA. Based on the findings, the following recommendations are

suggested; Organisations should apply a vigorous screening, recruitment and selection process of volunteers; Regular and continuous training of paraprofessionals and volunteers should be done by organisations rendering interventions to CABHA; Professional staff should provide structured and regular supervision to paraprofessionals and volunteers; Program planners should aim at filtering in monitoring and evaluation of the different components of the interventions. Future research should focus on how CABHA is integrated into general OVC interventions and on measuring the impact of the interventions.



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## **CHAPTER 7**

# **DEVELOPING GUIDELINES FOR SOCIAL WORK INTERVENTION WITH CHILDREN AFFECTED BY HIV AND AIDS**

### **7.1 INTRODUCTION**

Chapter 7 explains the process followed in developing guidelines for social work intervention with children affected by HIV and AIDS (CABHA). The chapter begins by giving an overview of the process followed in developing the guidelines, and this is done by explaining the different steps of the Delphi method that were implemented during this process. In each step, an explanation is given, focusing on the methodology, participants, data collection and results. The theoretical framework that informs the guidelines is also explained as well as the theory relating to the development of guidelines. The chapter concludes with a presentation of the guidelines for social work intervention with CABHA and a closing summary.

### **7.2 DEVELOPMENT OF GUIDELINES**

The Delphi method explained in the previous section provided an opportunity for the framework of the guidelines to be presented to stakeholders and to seek recommendations that can be incorporated into the final guidelines. An overview of the guidelines' purpose, objective and expected outcome will be explained first before presenting the final guidelines.

### **7.3 GUIDELINES FOR THE CURRENT STUDY**

The research guidelines were developed through a Delphi method. A Delphi method is targeted at achieving consensus through a series of questions presented to an expert panel in multiple iterations (Hsu & Sanford, 2007). When conducting a Delphi method, the researcher normally asks the questions, records, consolidates and transmits panel responses for each iteration until consensus is achieved (Avella, 2016). The study implemented a modified Delphi method. The modified Delphi method did not use online surveys but was presented as two rounds of online workshops where the relevant participants for each round were invited to participate. A detailed explanation of how the two rounds of the Delphi method were applied to the study is given in the next section.

#### **7.3.1 Round 1: Panel of experts**

This stage involved carefully selecting a panel of experts and identifying the disciplines invited to participate in the panel. Avella (2016) argues that selecting individuals with expert qualifications for panel membership is critical during this stage.

##### *7.3.1.1 Participants*

The participants were several experts who specialised in the field of caring for CABHA. The selection was not discipline-specific, so there was no restriction regarding the disciplines could participate in the workshop. Participants were invited by email, with weekly reminders being sent. A total of seven experts attended the first stage of the Delphi workshop, and they were all academics with diverse areas of expertise and experience in health, child and youth care, family interventions, community work and research. The demographic details of the participants are listed in table 7.1.

**Table 7.1 Demographic Details of Round 1 Panel of Experts**

Number	Designation	Area of Expertise
Panellist 1	Researcher	Blended teaching, family functioning
Panellist 2	Researcher	Child protection & family reunification
Panellist 3	Researcher	Family interventions
Panellist 4	Researcher	Child and youth care
Panellist 5	Researcher	Community work
Panellist 6	Researcher	Child and family studies
Panellist 7	Researcher	Public health

*7.3.1.2 Data collection*

The workshop aimed to discuss the research findings and develop a consensus on acceptable guidelines for social work intervention with CABHA. Due to Covid-19 restrictions, the workshop took place on an online meeting platform, Google meet. The panel was given background information about the aims, objectives, research questions and findings of the previous stages of the research. A framework of the guidelines based on the results of the previous stages of research was presented in a Table format (Table 7.2) which consisted of seven themes, sub-themes and facilitators. The sub-themes represented the action of how the themes would be implemented. The panel was asked to comment on whether the information presented flows logically and to give input on the clarity and feasibility of the guidelines. The panel members were asked to provide suggestions about additional information that they think is missing in the guidelines and to rank the themes in order of priority if the information did

not flow logically. All members of the panel were given a chance to debate suggestions until a consensus was reached on each theme and associated sub-themes.

**Table 7.2 Framework for Guidelines of Round 1 of the Delphi Workshop**

<b>THEME</b>	<b>SUB-THEME</b>	<b>FACILITATOR</b>
<b>1. Identification of the need</b>	<p><b>1.1</b> Screening and assessment (formal &amp; informal)</p> <p><b>1.2</b> Collaborations by different stakeholders (health, education, s/development, SAPS) and referrals</p> <p><b>1.3</b> Community involvement through awareness-raising campaigns, advertising and community members</p> <p><b>1.4</b> Referrals (structured)</p>	<p>- SWs, SAWs, CDWs, CYCWs, Community workers, Lay counsellors, Facilitators, Volunteers</p> <p>- SWs, Police, Health workers, CWs, Group Facilitators, Volunteers</p> <p>- Community leaders, forums and Advisory Boards</p>
<b>2. Psychosocial support</b>	<p><b>2.1 Counselling</b></p> <p>- Individual counselling for OVC, CABHA and caregivers</p> <p>- Family strengthening interventions</p> <p><b>2.2 Life skills training</b> focusing on:</p> <p>- behaviour change concerning health issues among children</p>	<p>- SWs</p> <p>- SAWs, CDWs, SWs (as case manager/coordinator)</p> <p>- Non-Professional staff (Group Facilitators, Volunteers, CWs)</p>
<b>3. Community-based Outreach</b>	<p><b>3.1 Health:</b></p> <p>- HIV Counselling and Testing (HCT) and adherence monitoring is done through home visits and mobile clinics</p> <p><b>3.2 Information dissemination</b></p> <p>- Facts on HIV and AIDS, prevention and HIV-related stigma</p>	<p>CHWs, Nurses, Lay counsellors</p>
<b>4. Education support</b>	<p><b>4.1 Early Childhood Development</b></p> <p>- Developmental assessment of children</p> <p>- Early identification of developmental problems</p> <p>- Placement in appropriate school</p> <p><b>4.2 Academic support</b></p>	<p>- ECD staff, Occupational Therapist, Social worker</p> <p>- Volunteers (tutors), CYCWs,</p>

<b>5. Parenting support</b>	<b>5.1 Parenting skills workshops</b> - bridging the generational gap, - HIV information and building communication - Strengthening different types of families (single fathers, skip a generation, extended, foster etc.) <b>5.2 Child protection and care</b> - Identification of children in need of care & protection  - Foster Care parent screening, recruitment and training - Creation of FC parent database - Parent support, family reunification and placement in foster care - Residential care monitoring	- SWs, SAWs, CYCWs, CDWs  - Volunteers, social service professionals, health workers, SAPS, educators - Social Workers  - Social Workers  - CYCWs & SWs
<b>6. Practical Support</b>	<b>Food security</b> - Link with resources that provide food parcels and Clothes - Teaching skills to grow own vegetable gardens <b>Family Economic empowerment</b> - Application for social security grants (FCG/CSG) - Training on income-generating skills - Training on job creation/job-seeking skills	- Community members, CDWs, and Social workers in collaboration with private, public, government and communities.
<b>7. Training, supervision, monitoring and evaluation</b>	7.1 Regular staff training and capacity building 7.2 Structured and regular supervision and debriefing of staff 7.3 Review and changing of interventions based on needs identified at the time of contact 7.4 Long-term follow-up did yearly 7.5 Yearly monitoring and evaluation of foster/residential and care	- Organisations - Social Work supervisors - Social Workers

### 7.3.1.3 Results

The panel reached a consensus about the flow of the themes and agreed that there was no need to rearrange the main themes. A few suggestions were made about the themes and sub-themes;



some were added, deleted and merged. The panel unanimously agreed that there was no need for the third column, which lists facilitators, as the social workers and organisations using these guidelines would have to fit them within their organisational structure. The panel felt that the column was rather prescriptive and not necessary. This means that if the guidelines come with a list of who should do what, it will limit some organisations that do not have those categories of staff stated in the guidelines. The final decision reached was that facilitators should be left to the discretion of those using the guidelines. The discussions that took place in relation to the sub-themes are discussed below.

***Theme 1: Identification of the need***

All the panel members reached a consensus that the theme of identifying the need for intervention was appropriate and that it made sense for it to be the first one in the guidelines. Four sub-themes were linked to this theme, and the participants suggested that a fifth sub-theme, 'participation by children', needed to be added. There was consensus on the idea given by one panellist that "*the voices of children need to be heard and they should be included in decision-making about their lives.*" The panel agreed that all children in the communities should be included in the process of identifying the need for intervention regardless of their HIV status, and this should include Orphaned and Vulnerable Children (OVC). Furthermore, the panel felt that the informal screening and assessment process needs to be standardised and aligned with the Children's Act 38 of 2005.

***Theme 2: Psychosocial support***

After debating about the sub-theme 'life skills training', the panel decided that the sub-theme should be 'capacity building for children' and that life skills should be included as part of the

activities under this sub-theme. They added that the topics covered under this sub-theme should be “*contextually relevant*” and include topics like cyberbullying, diversity and tolerance, rights and responsibilities, and economic freedom. Peer support training programmes across all educational levels and learning institutions were also suggested as one of the activities for consideration.

***Theme 3: Community-based Outreach***

This theme was left as is, but a few adjustments were made to the sub-themes. The panel of experts agreed that the sub-theme ‘health’ was better fitted under this theme but felt that the sub-theme ‘information dissemination’ should be a theme on its own. They further suggested that the theme ‘practical support’ should be merged under the community-based outreach theme related to the enabling of families and communities. The panel debated a strong objection to the sub-theme ‘food security’, and as one panellist felt, “*it presents an idea that families and communities are helpless and need rescuing.*” The consensus was reached that ‘family economic empowerment’ was a more appropriate term as a sub-theme under community-based outreach and that food security should be taken out.

***Theme 4: Education support***

The panel also supported the theme ‘education support’ and agreed it was relevant. Most panel members agreed that the sub-theme ‘early childhood development’ linked well with the main theme. However, a recommendation was made for the sub-theme ‘academic support’ to be merged under an alternative sub-theme, ‘resources.’ The panel felt that some of the issues discussed under academic support were more about resources offered to children.

***Theme 5: Parenting support***

The panel agreed that both sub-themes were fine but recommended that foster care be separated from child protection. They suggested ‘foster care support’ should be made a third sub-theme focusing on foster parent recruitment, training and support. Residential care support was also added as a fourth sub-theme. There was a suggestion that statutory social workers need to be visible in their role of foster care and residential care support and that this needs to be emphasised in the guidelines.

***Theme 6: Practical Support***

There was a consensus reached by all participants that this theme should be deleted and that some of the sub-themes should be merged under the community-based outreach theme. The suggestion was for the sub-themes of food security and family economic empowerment to be merged as one sub-theme: family economic empowerment and the food parcels to be taken out. This is the version presented in stage 2 of the Delphi and is discussed under stage 2.

***Theme 7: Training, supervision, monitoring and evaluation***

No changes were suggested for this theme, and all the five sub-themes linked to it were accepted.

The panel suggested that the information mentioned under the sub-themes should be reduced as it could confuse a reader and that all the sub-themes should be numbered so that there is a clear link to the main theme. At the end of this round, all the experts’ responses summarised all the contributions and suggestions made to the framework because, when using the Delphi method, the facilitator reviews and collates all the participants’ responses at the end of each

round (Mans et al., 2022). An adapted version of the framework was compiled and prepared for presentation to the second round of Delphi.

### ***7.3.2 Round 2: Panel of stakeholders***

The second stage of the Delphi method was a workshop with stakeholders working with children and families affected by HIV and AIDS. The workshop aimed to discuss the framework for developing guidelines for social work intervention with CABHA. Several stakeholders working with children and families affected by HIV and AIDS were invited by email.

#### ***7.3.2.1 Participants***

Invitations were sent to 25 organisations that work with OVC, CABHA and families affected by HIV and AIDS. The participants were recruited through snowball sampling, where they were asked to forward the invitation to other stakeholders they regarded as relevant and those providing interventions relating to OVC and children affected by HIV. Paraprofessionals such as child and youth care workers and social auxiliary workers were also invited to the workshop, but no response was received from any of these paraprofessionals. 12 participants participated in the workshop, including researchers and stakeholders working with CABHA from the disciplines of social work, psychology, physiotherapy, occupational therapy and academics. Five of these stakeholders were social workers. The demographic details of the stakeholders are presented in Table 7.3

**Table 7.3 Demographic Details of Stakeholders**

	Occupation	Field of expertise
Panellist 1	Lecturer	Research
Panellist 2	Lecturer	Research
Panellist 3	Occupational therapist	Rehabilitation & Counselling of OVC
Panellist 4	Physiotherapy	Community Outreach
Panellist 5	Social worker	Counselling, Community work, training & adherence support
Panellist 6	Social worker	Palliative care, respite care & family support
Panellist 7	Social worker	Facilitator of HIV training for lay counsellors
Panellist 8	Social worker	Community development
Panellist 9	Social worker	Employee Assistance Programme
Panellist 10	Researcher	Families and children
Panellist 11	Researcher	Vulnerable groups in society
Panellist 12	Psychology	Counselling

#### 7.3.2.2 Data collection

The second round of the Delphi workshop followed the same process as stage one, and the participants were presented with the background of the research, which explained the aims, objectives, methodology and findings. The stakeholders were presented with a modified framework for the guidelines based on the recommendations from the first round of Delphi. The summary was presented in a Table format (Table 2), and stakeholders were asked to give their input on the guidelines' logical flow, clarity and feasibility. They were also asked to make recommendations where they felt it was necessary.

#### 7.3.2.3 Results

Further recommendations were made in stage two by the stakeholders about the framework of the guidelines presented. This involved extensive discussions until a consensus was eventually



reached on the most appropriate aspects to be included in the guidelines and how the guidelines should flow. A further explanation and examples of the discussions are given in the next section under each part of the guidelines. The stakeholders agreed that the seven main themes identified in round one should remain as is and support the order in which the themes were presented. The following section will present only those themes and sub-themes where information was added, or changes were made.

***Theme 1: Identification of the need***

There was consensus that this theme and sub-themes were appropriate as a starting point in developing guidelines. The stakeholders raised concerns about implementing the first sub-theme for standardised screening and assessment. The concern was on the availability of resources to provide screening and assessment tools and the government's role in ensuring these tools' availability for all stakeholders. The stakeholders felt that organisations that do the initial screening and assessment need to be supported with the necessary assessment tools by the government, especially the Department of Social Development. The discussion was that all organisations should be part of the process of standardisation of the tools and that government should be responsible for funding and distribution of these tools. Another sub-theme, 'community engagement', was added, which relates to the involvement of relevant community members and existing community leadership structures in identifying the need for intervention. The panel felt that the community should play an important part in the initial stages of the intervention so that they form part of the planning of the intervention. The community structures identified include existing community leadership structures (such as civic

organisations), religious leaders (including all relevant religious denominations in those communities) and traditional leaders.

***Theme 3: Information dissemination***

The stakeholders had difficulty reaching a consensus on what sub-themes should be included and the topics to be covered under information dissemination. As one stakeholder explained, the debate was that *“the information should not only cover HIV-related information but should also cover general topics that affect OVCs in the communities.”* After much deliberation, the stakeholders agreed that information dissemination should also focus on giving communities information about how to identify children in need of care and the duty of community members to report such cases. For this reason, the two sub-themes of ‘identification of children in need of care by communities’ and ‘duty to report children in need of care by the community’ were added. A panel member commented that the use of social media should be considered in relation to information dissemination since *“it has the power to reach a large number of people than the conventional ways of communication.”* The panel agreed that social media is a powerful tool for distributing information. In the discussion, most stakeholders agreed that there were lessons learned from COVID-19, where social media connected people worldwide.

***Theme 4: Parenting support***

The panel of stakeholders suggested that the first sub-theme should be divided into two and that the first theme should remain as a parenting skills workshop. In contrast, the part on strengthening different types of families can be a second sub-theme. The panel felt that it was important to acknowledge the different types of families in South Africa since it is a democratic country that embraces diversity. A panel member expressed his views and said, *“we need to*

*make sure that this parenting support is inclusive and does not discriminate against people, especially the LGBTQI (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex) community.”*

The rest of the panel concurred that the sub-theme should reflect diversity and decided that the second sub-theme should embrace diversity and support different families. The panel further suggested that the explanation under foster care should be merged into ‘foster care parent recruitment, training and placement support by social workers’ and ‘residential care monitoring by social workers’, a fifth sub-heading. After implementing the changes, the panel argued that the suggested sub-themes would link unambiguously to parenting support.

The discussions during the Delphi method's two rounds allowed the panel of experts and stakeholders to discuss and give recommendations for the guidelines. After the discussions in each round, the researcher consistently checked with the panellists if they supported the recommendations other panel members gave during the workshop to ensure a consensus. This is a critical step in the process as the Delphi technique achieves consensus by progressively moving through sequential rounds of data collection with facilitated feedback after each round (Mans, Yogeswaran, & Adeniyi, 2022). After the final round of the Delphi, it was concluded that there was consensus about the final guidelines. Once the consensus workshops were concluded, the results of both workshops were analysed, and the changes suggested were used to develop the final framework for the guidelines. All recommendations and those from round one make up the final guidelines for social work intervention with CABHA, which are presented in table 7.4.

**Table 7. 4 Final Guidelines for Social Work Intervention with CABHA**

<b>THEME</b>	<b>SUB-THEME</b>
<b>1. Identification of the need</b>	1.1 Standardised screening and assessment 1.2 Collaborations by different stakeholders 1.3 Community engagement 1.4 Participation by children 1.5 Structured referrals
<b>2. Psychosocial support</b>	2.1 Counselling for children, caregivers and family members 2.2 Capacity building for children
<b>3. Information dissemination</b>	3.1 Health-related information workshops 3.2 Identification and reporting of children in need of care by the community 3.3 Identifying and tackling HIV-related stigma 3.4 Use of social media to distribute and discuss relevant information
<b>4. Community-based Outreach</b>	4.1 Health monitoring through home visits & mobile clinics 4.2 Disaster management 4.3 Family Economic empowerment
<b>5. Education support</b>	5.1 Early Childhood Development 5.2 Resources
<b>6. Parenting support</b>	6.1 Parenting skills workshops 6.2 Embracing diversity and supporting different types of families 6.3 Child protection and care 6.4 Foster care parent recruitment, training and placement support by social workers 6.5 Residential care monitoring by social workers
<b>7. Training, supervision, monitoring and evaluation</b>	7.1 Regular staff training and capacity building 7.2 Structured and regular supervision and debriefing of staff 7.3 Review and changing of interventions based on needs identified at the time of contact 7.4 Long-term follow-up done yearly 7.5 Yearly monitoring and evaluation of foster/residential and care

## **7.4 THEORETICAL FRAMEWORK**

Before presenting the guidelines, it is important to explain the theoretical framework that applies to them and the theory used in developing guidelines. The study is located within Bronfenbrenner's Ecological Systems Theory (EST). Kuo et al. (2014) argue that if we are to understand the needs of HIV-affected communities, we must recognise that people can be exposed to the effects of HIV multiple times, simultaneously and at different levels. The EST was chosen as the relevant theory that explains how HIV affects people at different levels. A detailed explanation of the applicability of EST is given in chapter 3 of the thesis. It explains that social workers need to understand the impact that parental HIV has on the child and other systems that the child interacts with. These are the microsystem (immediate environment such as the family), mesosystem (connections and relationships between parts of the microsystem), exosystem (environments that have an indirect impact on the child), macrosystem (blueprints of a particular society such as laws, regulations, norms and values) and chronosystem (major life transitions and historical events throughout a child's life). In relation to the current study, which focuses on interventions for children affected by HIV and AIDS, it is important for the social workers that provide services to these children to understand how the different systems within the child's environment impact the child before deciding on an appropriate course of action. Below is an explanation of how these elements were applied in the study.

### ***7.4.1 Application of the theoretical framework to the study***

#### ***7.4.1.1 Microsystem***

The findings of the study reveal that children who are affected by HIV are living in an environment with other people such as the parent/s or caregiver, siblings and other significant



adults/ extended family. All these people interact with the child regularly and have some relationship with the child. The relationships and transactions that occur between the child and these different people within his/her family system determine the type of interventions to be implemented by the social worker. When a parent is absent due to HIV illness or death, this often results in the changes of roles where the child either becomes a caretaker of the ill parent or other siblings in the absence of parents. The results also showed that the practitioners must understand the different types of families that the children come from. This helps them decide how they will provide the interventions and who will be involved. For example, it would be pointless to plan an intervention for mothers when the children come from families where the caregiver is not necessarily the mother or, in some cases, the mother is deceased. The initial stages of the research revealed the types of families served by the social workers as well as the unique traits that they possess. One example of a type of family that is often overlooked is a family with single fathers taking care of their children. A family-strengthening approach is recommended as fundamental to improving child welfare when working with OVC, including CABHA (Breckenridge et al., 2019; Kidman & Heymann, 2016).

Karakurt and Silver (2014: 81) argue that “problems within the family system can be viewed as the result of what occurs in the interactions between people in that all behaviours of members within a system affect the environment, and in return, the environment affects all members of a system”. Problems within a family system result from a disturbance in interactions among the family members. This disturbance in the context of CABHA is caused by the illness or death of the parent, which results in changes in the roles of all the people in the child’s microsystem. The family’s state of balance is negatively affected as the different family

members end up taking roles within the family that they were not prepared for due to the parent's ill health. This imbalance is evident in child-headed households and skip-generation families.

In some cases, the children must try to balance duties associated with being a child, such as school and play, with caregiver duties, cooking, cleaning and disciplining siblings. This may lead to disengagement amongst the siblings as they struggle to redefine their roles and find a balance in the level of family functioning. Achieving this state of balance is an essential task that needs to be achieved by the family. This behaviour ultimately indicates whether the family is functioning optimally or is dysfunctional. The guidelines will therefore provide social workers with a structure to assist CABHA and their families to find a balance during the disruptions caused by HIV and AIDS. The microsystem was applied in most guidelines since the child is the primary focus. Supporting the child alone would be useless if the family is not included in the intervention.

#### *7.4.1.2 Mesosystem*

Studies show that children with ill parents, specifically HIV/AIDS-related illnesses, may need to drop out of school or fall behind due to caring for an ailing parent (Andrews et al., 2006). This shows that the impact of HIV illness on a parent extends beyond the microsystem and affects the mesosystem. The mesosystem consists of the interactions between the child's microsystems, such as between the child's parents and teachers or school peers and siblings (Guy-Evans, 2020). This is the level where the microsystems do not function independently but are linked and influence one another. The results of this study also show that HIV illness in the family influences the child's school environment, hence the need for educational support

for CABHA. Therefore, the impact on the mesosystem was considered in developing the guidelines.

#### *7.4.1.3 Exosystem*

The exosystem incorporates other formal and informal social structures, which do not contain the child but indirectly influence them as they affect one of the microsystems (Guy-Evans, 2020). According to Andrews et al. (2006), families affected by HIV/AIDS have more economic difficulties due to the mounting medical costs. This means that when parents are ill from HIV-illness, they might struggle to make ends meet since their little money is spent on medication. When parents struggle financially, it means they cannot meet their children's needs. This shows the indirect effect that parental HIV has on the child because the parent's lack of financial stability due to illness ultimately affects the child as their basic needs are unmet. The findings of this study highlighted an issue in the mesosystem which negatively affects children. The findings revealed that caregiver unemployment causes financial distress, necessitating the intervention of social workers to provide some assistance to caregivers for them to obtain financial relief. This was considered when developing the guidelines for the social workers to understand the negative impact that the exosystem has on the child.

The extended family and the community also form part of the exosystem, and HIV impacts them since they step in and take care of the children without parents. As mentioned, this results in a shift in the roles within the extended family structure. Examples are grandparents taking care of grandchildren, fathers taking care of their children in the absence of the mother, neighbours stepping in to assist when parents are ill, and foster care parents. The role of the social worker is to help CABHA, families and communities understand where boundary shifts

have occurred and thus assist them in redefining and restructuring their roles so that everybody can understand their new roles. For example, in extended families taking care of CABHA, it would be important for the family member to understand that they have the primary responsibility of the child once the child is in their care, which is more than their role before when the parent was still around. Similarly, when children are placed in foster or residential care, they need to understand that this comes with new rules, which may be stricter than when they were alone at home or with their parents. This is also why the guidelines suggest close monitoring of foster care placements and residential facilities by social workers so that everyone knows where and what the boundaries, rules and roles are.

#### *7.4.1.4 Chronosystem*

This system encompasses changes that occur in a child's life and environment over a period of time. Elements within this system can be either external, such as the timing of a parent's death, or internal, such as the physiological changes that occur with a child's ageing. In relation to CABHA, the illness or death of the caregiver and the psychological implication this has on the child indicates the chronosystem's impact on the child. Studies (Breckenridge et al., 2019; Chitiyo et al., 2008; Nabunya et al., 2019; Tucker et al., 2016) show that children naturally suffer the grief of seeing their parents struggle with what usually is a long illness and the subsequent death of their parents. The impact of the chronosystem on the child is central to the development of the guidelines, as all events that occur in the child over a period of time affect the child differently at each stage. Paquette and Ryan (2001) argue that as children get older, they may react differently to environmental changes and may be more able to determine how

that change will influence them. Therefore, social workers must keep this in mind at every stage of the guidelines.

## **7.5 FINAL GUIDELINES FOR SOCIAL WORK INTERVENTION WITH CABHA**

The following section explains the final guidelines for social work intervention with children affected by HIV and AIDS. The section begins with an explanation of the guidelines' purpose, objectives and expected outcome. The last section ends with a presentation of the guidelines.

### ***7.5.1 Purpose of the guidelines***

The purpose of the guidelines is to provide a framework for intervention for social workers working with orphaned and vulnerable children, specifically those affected by HIV and AIDS in their home environment. The guidelines are meant to strengthen existing social work intervention methods and provide guidance to organisations directly involved in interventions for CABHA to ensure that these interventions support HIV-affected children, caregivers and communities.

### ***7.5.2 Objectives of the guidelines***

The objectives of the guidelines are to:

- Provide guidance to social workers and organisations rendering interventions to CABHA through a standardised framework for intervention.
- Afford social workers an opportunity to provide consistent and equal service delivery to CABHA in all communities.

### ***7.5.3 Outcome of the guidelines***

The expected outcomes of the guidelines are to:



- Build strong collaborations and networking amongst all stakeholders involved in interventions for CABHA.
- Provide standards for interventions to support children, parents/caregivers, families and communities affected by HIV and AIDS.
- Build a support network for CABHA within communities, so that community members adopt community-based interventions.
- Provide contextually relevant information to communities so that they are better equipped to deal with issues about HIV, OVC and CABHA.
- Equip parents/caregivers and communities of CABHA with skills to enhance their physical, social and economic well-being.

#### ***7.5.4 Presentation of the guidelines***

##### *7.5.4.1 Identification of the need*

Before planning any intervention, practitioners need to establish the need. Since the interventions are meant for children, it becomes necessary to identify those children needing care and intervention. The Children's Act (2005) gives clear guidelines to practitioners on identifying children in need of care. Still, these guidelines are generic and do not give specific details about needs relating to CABHA. In relation to the theoretical framework, consideration should be given to the transactions between parts of the family system during this stage. Literature has shown that CABHA is often taken care of by extended family after a parent's absence or death, and they must adjust to their new living arrangements (Breckenridge et al., 2019). In their new living arrangements, there is often an interaction between the child and the new adults, which means that the social worker needs to consider the impact of the different

parts of the family system when assessing during this stage. The social worker needs to establish the nature of the relationships between the child and the different family members in the child's immediate environment to make a proper assessment. For example, some families consist of skip generation where CABHA is being taken care of by grandparents who, according to Nabunya et al. (2019), often struggle to keep up with the pace of raising a younger generation.

- To identify the specific needs of CABHA, *screening and assessment* need to take place. Bartholomew-Eldredge et al. (2016) explain that a needs assessment is the first step in any programme planning. Screening and assessment can be done formally and informally, depending on who is the first point of contact with the children in need. The informal screening is done by volunteers and paraprofessionals, who then refer to the social worker for a proper and formal assessment.
- Collaborations by different stakeholders from different sectors, like health, education, social development, and SAPS, are also important in ensuring that wherever a child in need of care is identified, referrals to the appropriate service provider take place. This collaboration will ensure that information and referral protocols are shared so that every stakeholder knows exactly where the different needs can be addressed. Clear and standardised referral forms should be provided to all stakeholders and aligned to the Children's Act 38 of 2005.
- Community involvement is also an important part of identifying children in need, and this should involve existing community structures and community leaders. When community members are involved in the initial planning stage of intervention, they are most likely to support the intervention when it is implemented since they were consulted. This confirms

the findings by Sheer (2017), who argues that if children are to receive evidence-based interventions to maximize their developmental potential, it is important to monitor children within a community setting and also to understand how community-based organisations (CBOs) are positioned as potential providers of support. According to Maticka-Tyndale et al. (2007), the likelihood of buy-in of interventions from the communities increases where there is sensitization of communities (including religious leaders) and the inclusion of community representatives in the planning of the intervention.

- Participation by children in planning interventions is critical in ensuring that the children's voices are heard and that they become part of the solution. This does not necessarily have to be CABHA, but it should involve children in general, as this will eliminate the problem of isolating CABHA from other children. Involving the community during this stage will allow social workers to understand the need from the service user's point of view, the dynamics involved in the interactions within the different micro and macro systems, and the impact of these interactions on the child.

#### *7.5.4.2 Psychosocial support*

This guideline relates to the emotional support provided to the child and other relevant people in the child's environment to help them deal with issues relating to their vulnerability. Godberg and Short (2016) argue that one group of HIV-affected children with distinct vulnerabilities are those living with HIV-infected or AIDS-ill adults. Therefore, organisations rendering interventions to OVC must acknowledge, and address needs specific to CABHA when they have children living with an HIV-infected caregiver in their programs. Parental illness may result in mental hardship, loss of freedom for the kid owing to caring for a sick loved one,

disruptions to education, isolation, the possibility of familial exploitation, and stigmas connected with being an AIDS orphan (Tucker et al., 2016). Psychosocial support is meant to help these children deal with the emotional distress, stigma and vulnerability associated with being CABHA. Children who live in poverty and have lost a parent due to HIV-related illness are more likely to have decreased coping mechanisms (Breckenridge et al., 2019).

- As part of psychosocial support, counselling should be provided to CABHA to assist them in dealing with the emotional burden of being orphaned and vulnerable because of HIV and AIDS. HIV also decreases the parents' ability to take care of their children and adds to the vulnerability of children. Counselling should not only focus on the child alone but should adopt a family strengthening approach, which also supports caregivers and other family members. Through counselling, the social worker can help the children and families understand the roles that have changed and position themselves in their new roles.
- Capacity building for children can also be incorporated into psychosocial support, where children are taught various life skills that will encourage positive life choices and equip them with relevant information to deal with stigma and discrimination. This is an ongoing task that should be encouraged by all stakeholders that work with children in general.

#### *7.5.4.3 Information dissemination*

Research shows that HIV-affected families are at increased risk of stigma in the community, not achieving their educational goals, and economic insecurity (Breckenridge et al., 2019). Stigma is usually associated with a lack of knowledge from those who discriminate against others. Because of the stigma associated with HIV and AIDS, children living in HIV-affected households are usually ostracised both in their community and at school (Chitiyo et al., 2008).

It is important for practitioners doing interventions to ensure that the communities and families have the correct information regarding HIV and AIDS to dispel any myths relating to HIV and AIDS and to reduce the incidences of stigma.

The guidelines, therefore, suggest information dissemination, where regular workshops on health-related information and other information that affect OVC and CABHA are to be held within communities to ensure that correct and relevant information is shared.

- Practitioners also need to share information with communities on the role of community members in identifying and reporting children in need of care. This is most likely to increase community involvement in addressing the issue of vulnerable children.
- Community forums need to be held to identify HIV-related stigma and discrimination in communities and explore the role community members must play in addressing these issues.
- The use of social media to distribute and discuss relevant information should be encouraged by organisations rendering interventions, as information shared through these platforms will reach a large audience quickly.

#### *7.5.4.4 Community-Based Outreach*

Previous research (Stansert Katzen et al., 2020) identified the benefit of using healthcare workers in community-based health interventions. A study by Tomlinson et al. (2016) revealed that integrating mobile health units with home-based ECD and nutrition services improved the community linkages with the primary healthcare facilities in under-served populations. Additionally, Ssewamala et al. (2016) suggest that innovative family-level economic strengthening programs, including psychosocial interventions for young people, may have positive developmental impacts on education, health, and psychosocial functioning.



The guidelines recommend that community-based outreach programs should be encouraged, which focus on bringing health services closer to communities. This is done through home visits conducted by community health workers who conduct health monitoring and follow up of clients and report to the community health centres. This is helpful for ARV adherence counselling, and tracking clients lost to follow-up or defaulting on their medication.

- Disaster management protocols for intervention should be established to prepare for future disasters. This is to ensure that all stakeholders are well-equipped with information on what to do during periods of disaster and the role of each stakeholder. These protocols are meant to protect the rights of CABHA and ensure service delivery continues. Communities need to be part of formulating these protocols as they are very often the first point of contact during periods of disaster.
- Encouraging family economic empowerment by enabling families of CABHA with income generating, job creation and job seeking skills.

#### *7.5.4.5 Education support*

Without proper education, orphaned children may be at higher risk of poverty and may be less knowledgeable about the impact of AIDS and the need for protection (Breckenridge et al., 2019). Research shows that children living with HIV-infected parents are most likely to experience difficulties in school due to increased absenteeism because they have to take care of a sick parent (Breckenridge et al., 2019; Tucker et al., 2016; Visser et al., 2015). This means they miss out on schoolwork and may display poor academic performance. Educational support, therefore, is one of the important steps suggested in the guidelines.

- Professionals with specialised skills in relation to Early Childhood Development (ECD) should be involved in the developmental assessment of children to encourage early identification of developmental problems and ensure that those affected children are placed in appropriate schools that cater to their developmental needs.
- Resources for academic support should be provided to CABHA to encourage them to remain at school and complete their schooling. Providing children with the resources or linking them to resources will assist with their academic development and promote resilience. This requires collaboration between the education sector and those stakeholders that provide interventions to CABHA.

#### *7.5.4.6 Parenting support*

Previous studies have shown that HIV negatively impacts parents' ability to take care of their children (Breckenridge et al., 2019; Sherr et al., 2016). This means that parents or caretakers responsible for CABHA need some parenting support. Supporting caregivers and strengthening the family environment in which HIV-affected children are raised is necessary to improve children's welfare (Kidman & Heymann, 2016). Schenck (2009) suggests that interventions should build caregiver and community capacity by enhancing traditional kinship- or community-based support systems.

- Parenting skills workshops are a form of parenting support that assists those caregivers taking care of CABHA. These parenting skills workshops should embrace diversity and support different types of families. This links very well to the EST that requires practitioners

to the impact of HIV illness on all the systems that interact with the child to ensure that the interventions target the right audience and deal with issues specific to those types of systems.

As part of psychosocial support, child protection and care need to be ensured by social workers through statutory intervention where necessary. Those social workers who do not have the mandate to conduct statutory intervention should be supported when they identify child protection cases. This is in line with the Children's Act (2005) which recommends social work intervention for cases where children in need of care have been identified. Furthermore, the guidelines suggest that statutory social workers should do proper foster care parent recruitment, training and placement support. This need entails regular follow-up of foster care placements and residential care facilities to check case compliance and suitability and to update information at least twice a year.

#### *7.5.4.7 Training, supervision, monitoring and evaluation*

Programs using paraprofessional staff have been shown to provide more tangible support than those using volunteers (Thomas et al., 2020). Additionally, Kidman et al. (2014: 305) suggest that “programs that invest in compensation and extensive training for home visitors are better able to serve and retain beneficiaries, and they support a move toward establishing a professional workforce of home visitors to support vulnerable children and families in South Africa.” This means that there is some benefit in using volunteers and paraprofessional staff in implementing interventions. The guidelines also suggest that regular staff training and capacity building should be done, especially in cases where organisations make use of paraprofessional staff and volunteers. Structured and regular supervision should also be provided to staff providing interventions to CABHA. This will allow them to debrief and seek guidance about

challenges they encounter during their work. This will ensure they are better equipped to support CABHA, families and communities affected by HIV.

Regular monitoring and evaluation of programs should be incorporated into the planning of the intervention so that there is long-term follow-up. The evaluation should be done yearly so that changes in the interventions can be implemented if need be. The changes are implemented based on the needs identified at the time of the evaluation to ensure that the interventions remain contextually relevant and adapt to changes in the environment of CABHA. The COVID-19 pandemic and the restrictions implemented are typical examples of how the world had to adapt to environmental changes.

The guidelines have been developed to assist social work practitioners working with CABHA in having a structured intervention that can be used across different communities. Children affected by HIV and AIDS can be found in all communities and are often classified as part of OVC or children needing care and protection. Multiple stakeholders often render different interventions with CABHA, but these interventions are not synchronised. There is often ambiguity when it comes to referrals of problems related to vulnerability linked to being an HIV-affected child. This is usually caused by the fact that there is no clear distinction between OVC and those children made vulnerable because of HIV and AIDS. These guidelines have been developed to assist social workers and other practitioners working with CABHA to have a point of reference when dealing with HIV-affected children. The guidelines guide professionals on how to support parents, families and communities of CABHA. The guidelines are not only for social workers but can be used by paraprofessionals who form an important

part of interventions for CABHA. The guidelines promoting social inclusion are meant to encourage practitioners to design and implement interventions from a family systems approach that considers the different systems interacting with CABHA. Even though the guidelines are aimed at interventions for CABHA, they are not meant to isolate CABHA from other children in need of care. Still, they are meant to be benchmarks for interventions to support children, parents/caregivers, families and communities affected by HIV and AIDS.

## **7.6 CONCLUSION**

This chapter presents a detailed explanation of the development of guidelines for social work intervention with CABHA. The chapter begins by giving an overview of the Delphi method and the different stages involved in developing the framework for the guidelines. A theoretical framework which includes the family systems theory and guideline development, was presented to give context and explain how the guidelines were formulated. The chapter concludes with a description of the guidelines, which are meant to give social workers and other practitioners working with CABHA a point of reference when dealing with cases of HIV-affected children. Even though the guidelines are aimed at interventions for CABHA, they are not meant to isolate CABHA from other children in need of care. Still, they are meant to be a benchmark for interventions to support children, parents/caregivers, families and communities affected by HIV and AIDS.



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## **CHAPTER 8**

### **DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

#### **8.1 INTRODUCTION**

HIV and AIDS decrease the parenting capacity of caregivers when they become ill from HIV-related illnesses, which leaves their children vulnerable and with no visible means of care or support. This highlights the need for interventions for children affected by HIV and AIDS to ensure their needs are met. This study developed guidelines for social work interventions for children affected by HIV and AIDS. This chapter concludes the study's findings, which are done by presenting summaries of research findings that were presented in the previous chapters of the thesis. The chapter begins with a brief explanation of the research problem, aim and objectives. Summaries of all the study findings are presented in relation to the research aim and objectives. An overall conclusion of the findings is also presented, ending with recommendations for practitioners, social work education and future research.

#### **8.2 STATEMENT OF THE RESEARCH PROBLEM**

The AIDS and HIV crisis is one of the greatest health epidemics that has affected the world for over three decades. Global statistics reveal that the number of HIV-infected people has increased since a decade ago, from an estimated 34 million PLWH in 2012 (UNAIDS, 2012) to 38 million in 2022 (UNAIDS, 2022). Of the 147 million orphans (0–17 years) globally, 14.9 million [confidence bounds: 11.9 million–18.3 million] lost one or both parents due to an AIDS-related cause in 2021 (UNICEF, 2022). Children are often left without adult supervision when the parent or caregiver ultimately dies from HIV and AIDS-related illnesses, leaving



them vulnerable to exploitation. The good news is that over the past decade, the global community and individual countries have progressed toward addressing the needs of HIV-affected children and families (Kidman & Heymann, 2016). Several interventions have been implemented across Africa to support children affected by HIV and AIDS (Betancourt et al., 2014; Bhana et al., 2010; Ssewamala et al., 2016). However, these interventions are implemented by various stakeholders independent of each, and the social worker's role is not clearly defined in these interventions.

Furthermore, the Children's Act (2005) also does not give clear guidelines on implementing interventions with CABHA. The Act only focuses on general HIV testing, counselling and confidentiality of children's HIV status, and HIV testing for foster care and adoption purposes. However, CABHA can be classified as children in need of care and protection as defined by the Children's Act 38 of 2005, as the circumstances, they end up in due to parental/caregiver absence often warrants social work intervention because these children are vulnerable and in need of care. The National Strategic Plan (NSP) 2017-2022 that the government of South Africa introduced provides a framework from which different stakeholders involved in HIV, TB and STI programs can work and develop intervention programs (SANAC, 2017) but does not give clear guidelines for social work intervention. In the past, social workers working with HIV-affected clients had to be adept at formulating best practices from what was available in their settings and communities (Links, 2001). Therefore, this study's motivation was to develop guidelines for social work intervention with children affected by HIV and AIDS.

### **8.3 RESEARCH AIM**

The main of the study was to develop guidelines for social work intervention with children affected by HIV and AIDS.

### **8.4 RESEARCH OBJECTIVES**

The objectives of the study were to

- Identify and explore best practice interventions used with children affected by HIV for community-based care through a systematic review,
- Identify and describe the intervention models used when working with children affected by HIV and AIDS,
- Explore the experiences in using interventions aimed at children affected by HIV and AIDS,
- Develop guidelines for social work intervention with children affected by HIV and AIDS.

### **8.5 DISCUSSION OF THE RESEARCH FINDINGS**

The study was conducted in two phases. The first phase was a needs assessment to understand the research problem better, and the second phase focused on developing guidelines for social work intervention with children affected by HIV and AIDS. The first phase focused on answering the first 3 objectives, while the second phase focused on the last objective. A summary of the research study is presented in relation to the study's objectives. The summary will explain how each of the study objectives was achieved.

### ***8.5.1 Phase 1: Needs Assessment***

As mentioned in the previous section, the study's first objective was to identify and explore best practice interventions used with children affected by HIV for community-based care through a systematic review. This objective was achieved during the first stage of the study, where a systematic review (SR) was conducted, which aimed to identify best practice models to increase support for children affected by HIV and AIDS by making use of the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework. The SR focused on articles that reported on interventions for CABHA that were implemented across the African continent and found that most of the interventions mainly used approaches that addressed psychosocial support and empowerment of families of CABHA.

#### ***8.5.1.1 Objective 1***

The results of the SR revealed that there is value in investing in psychosocial support for CABHA as this encourages positive relationships between caregivers and children in families affected and reduces the risks of mental health problems in children. This confirms a recommendation by Allen et al. (2014) who suggest that interventions should not only focus on providing life-saving medical treatment but also have the responsibility to attend to the psychosocial needs of the growing population of children affected by parental HIV/AIDS in South Africa. This further supports previous research (Sherr et al., 2016), which claimed that community-based interventions that aim to alleviate caregiver depression in the presence of HIV might help to disrupt adverse child outcomes. Psychosocial support, therefore, is an important part of interventions for CABHA as it plays a key role in promoting healthy relationships within the families of CABHA.

In HIV-affected communities, adults caring for children who have been orphaned and made vulnerable by HIV often face financial, social, and educational costs associated with care provision (Heymann et al., 2007). This financial stress indirectly affects CABHA because their needs are not fully met due to the financial strain experienced by the caregivers. The SR also revealed that interventions that focus on family economic empowerment might relieve the financial burden experienced by caregivers brought about by the inability to provide for the needs of CABHA. This means that interventions aimed at enhancing the psychosocial functioning of children affected by HIV should focus on psychological support and include family economic empowerment by providing opportunities for economic growth for families in poorly resourced communities. Family economic empowerment was recommended in previous studies (Ssewamala, et al., 2016), to be one of the effective means of reducing depression among children orphaned by AIDS. Economic empowerment of families enables families with the financial stability to provide the necessary care and support to CABHA.

On the contrary, Karimli et al. (2019) caution that programs that aim solely at increasing household income may be less beneficial to children's mental health than those aimed specifically at reducing the impact of poverty on children. Interventions that provide economic empowerment should not focus on short-term economic relief but on enabling families of CABHA with skills that have long-term benefits. This means that interventions that focus on economic empowerment must also look at the sustainability of such programs to ensure that families can maintain themselves long after the intervention has ended. This links well to the findings of the SR on using the RE-AIM framework as an important tool used in the design, implementation and evaluation of community-based intervention programs.

The RE-AIM framework emphasises that when designing interventions, practitioners need to be able to measure the extent to which the intervention can reach the target population, be effective by achieving its intended outcomes and the unanticipated negative effects, be adopted by the target institutions, implement intended objectives and maintain the effectiveness in recipients over time (Glasgow et al., 1999). Using the RE-AIM framework to appraise the studies revealed that interventions are most likely to be successful if communities are included in the planning and implementation of the interventions and when there is long-term follow-up. This is the most effective way that the impact of the intervention can be evaluated, as Thurman et al. (2016) mentioned that a one-year follow-up post-intervention may be too short to capture the full range of potential program effects. Furthermore, the results showed that interventions need to be flexible to the socio-cultural context of the communities where they are implemented. Long-term follow-up should be part of the design of interventions. As Betancourt et al. (2011) explained, this highlights the importance of understanding local manifestations of health problems when planning interventions for HIV/AIDS-affected children. Isaacs et al. (2018) also agree that practitioners must implement flexible interventions tailored to a specific context. Therefore, the SR's findings suggest that practitioners must ensure that long-term follow-up is included when planning intervention programs, as this will ensure the intervention's long-term effects and provide an opportunity for evaluation. Furthermore, when planning interventions, practitioners must also ensure that those interventions are customised for particular cultural settings where they are meant to be implemented.



### 8.5.1.2 Objective 2 & 3

The second objective was to identify and describe the intervention models used when working with children affected by HIV and AIDS. This objective was achieved by conducting interviews with stakeholders from relevant organisations that provide supportive services to CABHA. The third objective was to explore the experiences in using interventions aimed at children affected by HIV and AIDS. This objective was achieved by interviewing social workers involved in interventions for CABHA. There were similarities in the participants' responses to these two stages of data collection; the results were compared and contrasted with coming up with themes. One of the reasons for the similarities is that some of the stakeholders in the first round of data collection were also social workers, which means that their reflections were similar to those of social workers in the next stage of data collection. There were also major similarities in the interventions provided in the organisations, even if no social workers were employed. The results of these stages showed that two processes are involved in interventions for CABHA. The first stage entails the processes involved in establishing the need for intervention for CABHA, and the second stage consists of the implementation of the intervention. These two stages were reported separately in two different chapters.

The first part of the findings reports that interventions aimed at CABHA must be well structured to ensure that they provide the correct and relevant services. The findings revealed that the first step is to identify children needing the services to ensure that an intervention will be relevant. This is done through assessment, referral and creating awareness in communities. An assessment is done before deciding on the actual intervention; this can be done informally by volunteers or paraprofessional staff who refer to a designated social worker for further

investigation and intervention. However, Mann et al. (2012) and Thurman et al. (2014) caution against using untrained staff since they may not have the necessary skills to deal with complicated client issues and may compromise the quality of care. Mann et al. (2012) further argue that quality care is compromised when using volunteers or non-professional staff due to a lack of appropriate training and supervision of care personnel.

In contrast, Kidman et al. (2014) support the use of non-professional staff and argue that intervention programs that provide remuneration and extensive training for home visitors are better able to serve and retain clients. The use of non-professional staff was also identified as useful in a study by Stansert Katzen et al. (2020), who found home-visiting by community health workers to be beneficial in an intervention for maternal and child health. Kidman et al. (2014:305) further validate the use of these types of intervention programs that “support a move toward establishing a professional workforce of home visitors to support vulnerable children and families in South Africa”. Providing proper supervision and training of these staff components is very important for the success of interventions and for ensuring accountability. This indicates that most organisations follow guidelines provided by the Children’s Act 38 of 2005 that children needing care must be referred to a designated social worker for investigation and intervention. Additionally, this is consistent with the first step of intervention program planning and design, which, according to Bartholomew-Eldredge et al. (2016), involves the planner assessing the problem and source of the problem before beginning the intervention program. Creating awareness in the communities identified in the findings is a collaborative process between the communities and all the stakeholders that provide services to CABHA. This finding is supported by Tumwesige et al. (2021), who state that community

collaborations and partnerships are particularly important when implementing interventions, which demand a high level of communication and coordination among numerous stakeholders.

The second part of the results reports on the implementation of interventions for CABHA and finds that the types of interventions the organisations provide are structured according to the client's needs. Furthermore, there is no universal way to conduct interventions aimed at CABHA and each organisation structures interventions based on the needs identified. The interventions provided to CABHA focus on different kinds of supportive services that different role players facilitate. The key role players in implementing interventions are a combination of professionals, paraprofessionals and volunteers who occupy various positions and perform different tasks. It is also imperative to note the crucial role of social workers in the coordination of interventions and in bringing the needed resources together to work for the benefit of the CABHA, families and the community. Social workers also need to consider the uniqueness of the families and communities where interventions are implemented. The social worker often takes the role of a case manager in these interventions giving guidance to the other role players. A case manager is a practitioner who assumes primary responsibility for assessing a client's needs and arranging and coordinating the delivery of essential goods provided by other resources and services on behalf of a specific client (Hepworth et al., 2010). This highlights the importance of coordinating services to ensure that everyone plays their role in the intervention. This confirms the importance of having guidelines for social workers to ensure consistency in service delivery.

The results also showed that the level of interventions that social workers may use depends on the needs of the CABHA that have been identified, and interventions might focus on

individuals, families or communities. Even though the child is the centre of the intervention, the beneficiaries often involve the caregivers/parents and other family members. This is because HIV negatively impacts the affected individual and their household livelihoods and community safety nets (Nabunya, 2019). Involving the family members is also beneficial for the microsystem as they are also affected by the illness of the family member, which in turn affects the whole system. Involving the family may assist the functioning of the whole system return to a state of balance. This links well to the Ecological Systems Theory that informs the study, which explains that to understand the individual, it is not enough to describe them in the context of their family (the micro context). Still, we must also take into account how various systems interact with the individual and with each other (the meso context) as well as their context of daily living (macro system) (Christensen, 2010). Therefore, interventions should target the children and involve all other systems that interact with the child. Involving the other systems that interact with the child will ensure that the impact of HIV on the child is tackled from all possible angles.

### ***8.5.2 Phase 2: Development of Guidelines***

Over the past decade, the global community and individual countries have progressed towards addressing the needs of HIV-affected children and families. Still, support has most often been delivered through targeted programs which do not fully meet the needs of CABHA (Kidman & Heymann, 2016). The second phase is linked to the fourth objective of the study and focuses on developing guidelines for social work intervention with children affected by HIV and AIDS. This objective was achieved by conducting a Delphi method which involved two rounds of discussions through workshops with experts and different stakeholders to discuss the study

findings, present a framework for the guidelines and reach a consensus on the acceptable guidelines. After the presentation of the framework on both rounds of the Delphi method, there was consensus on seven themes for the guidelines.

#### *8.5.2.1 Identification of the Needs*

The first theme relates to identifying the needs of CABHA through structured formal and informal screening and further intervention. The involvement of the children, communities and relevant stakeholders is critical. This means those planning interventions for CABHA need to adopt a collaborative approach that includes children and community members of the area where the intervention will be implemented. This confirms the findings of Burke et al. (2015), who found that the inclusion of a variety of community-based organisations in the planning of a program helps in the development of interventions that are attractive to both community members and professionals who may deliver such programs. Tumwesige et al. (2021) also agree that program planners “committed to engage communities in the process need to invest in relationships, maintain trust, work with both the formal and informal leadership, and sustain the commitment of community organisations and leaders to mobilise the communities effectively.” Collaborations between stakeholders working with CABHA and communities are an important source of support for communities-based interventions. The critical role of collaborations amongst stakeholders and partnerships with the communities is therefore important in increasing the likelihood of success for interventions. Paraprofessionals and volunteer staff bring valuable input to the interventions, and they should be provided with the necessary support, such as regular supervision and capacity building. Previous studies (Kidman et al., 2014; Thurman et al., 2014) have shown that paraprofessional-driven programs provided



greater interaction with the CABHA and more tangible support to caregivers of CABHA. This means that identifying the need for intervention is a process that needs to be well coordinated between those involved in conducting the initial assessment, the community and other stakeholders. The formal and informal assessment has valuable input in identifying the need. Social workers, therefore, have the duty to ensure that all assessments and referrals are conducted in line with the relevant legislation like the Children's Act and that the child's interests are of paramount importance in any decisions taken for the child.

#### *8.5.2.2 Psychosocial Support*

The second theme concerns psychosocial support for CABHA provided through counselling that focuses on a family strengthening approach, including caregivers and other family members. Tucker et al. (2016) argue that parental illness may trigger emotional distress for the child and loss of freedoms due to caring for an unwell loved one, as well as disruptions to education, isolation, potential exploitation by family, and stigma associated with AIDS orphan status. The death of a parent exacerbates this emotional distress due to AIDS-related illness. Orphaned children face many challenges due to parental loss and poverty, which can impede their physical and emotional growth and development. (Tumwesige, et al., 2021). The psychosocial support is meant to assist children in dealing with the emotional distress that CABHA usually experiences as a result of losing parents due to HIV.

#### *8.5.2.3 Information Dissemination*

The third theme is information dissemination on important health-related information, HIV stigma and the role of community members in identifying and reporting children in need of care. This is not only for CABHA but for all communities where OVC and CABHA can be

found. This confirms that there is still space for social media, which was highlighted as a useful tool for information dissemination.

#### *8.5.2.4 Community-Based Outreach*

The fourth theme is community-based outreach programs that focus on bringing health services closer to communities through home visits and health monitoring conducted by community health workers who follow up on clients and report to the community health centres. This supports the findings by Thurman et al. (2014) that home-visiting programs provide some benefits to families affected by HIV and AIDS. Still, there is a need for programs serving HIV-affected families to add focused, evidence-based psychological interventions to supplement traditional home visiting.

Furthermore, this also corresponds with the findings of Stansert Katzen et al. (2020), who also recognised the benefit of using healthcare workers in community-based health interventions. However, Stansert Katzen et al. (2020) advise that it is important to pay more attention to the structural and socioeconomic determinants of health for a complete intervention. This statement implies that guidelines that focus on the health aspect in community-based outreach should not only look at the physical features of health but should also focus on other factors that contribute to the general health and well-being of CABHA. This is why the guidelines also highlight that community-based outreach programs filter in the economic empowerment of families of CABHA to enable families deal with the economic stress brought by HIV. Research shows that children living in communities affected by HIV/AIDS may benefit from innovative family economic empowerment interventions. (Han et al., 2013).

#### *8.5.2.5 Education Support*

The fifth theme focuses on education support for CBHA through promoting Early Development for younger children and academic support for older children. Parental illness due to HIV has been reported to cause disruptions to the child's education, often leading to poor academic performance (Breckenridge et al., 2019; Tucker et al., 2016; Visser et al., 2015). This is because these children may need to drop out of school or fall behind due to caring for a sick parent. Education support provides these children with resources to use to enhance their education and also provides them with an opportunity to improve their academic performance. The education support does not take away the disruptions caused by the circumstances around caring for a sick parent, but it is there to ensure that the impact of these disruptions is minimised.

#### *8.5.2.6 Parenting Support*

The sixth theme emphasises the provision of parenting support for caregivers of CABHA, and this should take into account the different family types, embrace diversity and encourage social inclusion. Studies suggest that caregivers caring for CABHA often face challenges associated with the increased responsibility of caring for additional children within the household (Littrell et al., 2011). The provision of parenting support becomes critical in interventions to ensure that those caring for CABHA feel supported and to help them deal with the financial, social and educational costs they incur. Lachman et al. (2014) also agree that parenting interventions that locate positive parenting within a wider ecological framework by improving child behaviour problems and caregiver depression might buffer against risks for poor child mental and physical health outcomes in families affected by HIV/AIDS and poverty. Parenting support allows the social worker to provide caregivers with the necessary support to deal with the challenges

associated with caring for CABHA and rebuild the relationships within the microsystem that are strained due to a change in roles.

#### *8.5.2.7 Training, supervision, monitoring and evaluation*

The last theme focuses on organisational development with an emphasis on regular training, supervision and capacity building of non-professional staff. Kidman et al. (2014: 307) argue that “programs that invest in compensation and extensive training for home visitors are better able to serve and retain beneficiaries”, and they support a move toward establishing a professional workforce of home visitors to support vulnerable children and families in South Africa”. Incorporating regular monitoring and evaluation of programs into the planning and implementation of the intervention is encouraged as part of the guidelines. This is in line with the suggestions (Allen et al., 2014) that it is important to modify and evaluate psychosocial interventions in low-resource settings that are affected by a high prevalence of HIV. The modification confirms the need for interventions to be flexible and adapt to the context where they are implemented. This means that the monitoring and evaluation process will allow social workers to adapt interventions to fit the different communities where they are implemented. Regular monitoring and evaluation also allow social workers to identify gaps in intervention and make the necessary changes for the future.

## **8.6 LIMITATIONS**

It is important to acknowledge that most research studies come with limitations. Limitations are often present in even the most carefully planned research study (Fouche et al., 2021). Creswell and Creswell (2018) explain that it is helpful to acknowledge potential limitations of the study as they represent an acknowledgement of weaknesses so that future studies will not

suffer from the same problems. The current study also had limitations which are explained below.

- The snowball sampling technique limited the number of people who participated in stages 3 and 4 of data collection as the study relied on others to identify participants that met the criteria. “While it is obviously desirable to do one’s best to maximize a response rate, it is also important to be open about the limitations of a low response” (Bryman, 2016: 186). There is a possibility that key participants may have been missed and not participated in the study since the participants were received via contact persons in the organisations or referrals by other participants. This may have resulted in fewer participants responding to the invitation to participate.
- The selection criteria for participants in stages 2 and 3 of data collection referred to CABHA. They omitted OVCs, as it became apparent during data collection that CABHA is very often integrated into services for OVCs. This means that some organisations that render services to CABHA and contain critical information about CABHA were missed since their focus is on OVCs.
- Government social workers responsible for statutory intervention for OVC and children in general were not included in the study due to service delivery pressure and operational constraints that prevented their participation in the study. This has limited the study's representativeness and generalisability as the government sector is not represented in the sample.



## 8.8 RECOMMENDATIONS

The following are the recommendations from the study:

### 8.8.1 Recommendations for Practice

- Practitioners need to collaborate with community members and all relevant community structures before attempting to plan community-based interventions to ensure that the community is part of the interventions' development.
- Practitioners should consider the role of traditional leaders and religious leaders in communities where interventions are planned.
- Interventions should be relevant to the socio-cultural context of the communities where they are implemented and cater for diverse populations.
- The RE-AIM framework can be used as a valuable tool in planning interventions to ensure a 'buy-in' of the intervention by the relevant stakeholders and communities.
- Program planners should aim to filter in monitoring and evaluating the different components of the interventions.
- Practitioners should incorporate regular and continuous monitoring and evaluation of interventions every 6 to 12 months so that adjustments can be made if necessary.
- A stakeholders' forum can be formed, consisting of practitioners working with CABHA to share resources and information.
- The organisations involved in the multisectoral collaborations should work together with social workers and create referral forms that should be used by all non-professional staff when making referrals.

- The informal assessment and referral process needs to be standardised and endorsed by all the stakeholders as it is conducted by non-professional staff and volunteers who may not possess the necessary skills to assess children in need of care properly.
- Organisations should apply a vigorous screening, recruitment and selection process of volunteers.
- A registered professional staff of the different disciplines should provide structured and regular supervision to paraprofessionals and volunteers that function under their field of practice.

### **8.8.2 Recommendations for education**

- Higher education Institutions (HEIs) need to provide training for paraprofessionals in the different fields of organisations working with CABHA
- Collaboration needs to take place between the organisations and HEIs to provide courses that offer continuous professional development to professional and non-professional staff
- HEIs should provide more training to social workers and practitioners on planning, implementing and evaluating successful intervention programs
- Long-term partnerships between organisations dealing with OVC and CABHA, and HEIs should be formed to provide practice education opportunities for students
- Future research should focus on evaluating the role of non-professionals and paraprofessionals in the implementation of interventions and how these categories of staff can be utilized optimally in the interventions for CABHA.

- Future research should focus on how CABHA is integrated into general OVC interventions and on measuring the impact of the interventions.
- More research is needed throughout SA to understand CABHA within varied cultural contexts. This would allow program implementers to design interventions tailored to fit the different cultural contexts of SA.

## **8.9 CONCLUSION OF THE THESIS**

The AIDS epidemic has been around for quite some time, but despite all the new developments in the care and treatment of HIV-infected people, many still die from HIV-related illnesses. Many children are left to fend for themselves as their parents and caregivers die or become too ill to fulfil their parenting responsibilities. Children are left vulnerable and, with no means of support, are in need of social work intervention. This study aimed to develop social work intervention guidelines for children affected by HIV and AIDS. This thesis provides a detailed explanation of the research study done to develop those guidelines. The guidelines are meant to assist social workers with intervention standards to support children, parents/caregivers, families and communities affected by HIV and AIDS.

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# APPENDICES

## Appendix 1: Ethical clearance letter



### DEPARTMENT OF RESEARCH DEVELOPMENT

21 August 2017

#### To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape, at its meeting held on 01 September 2015, approved the methodology and ethics of the following research project by: Ms Ms N Lukelelo (Social Work)

Research Project: Guidelines for social work interventions with children affected by HIV and AIDS.

Registration no: 15/6/30

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias  
Research Ethics Committee Officer  
University of the Western Cape*

Febvre Day X17, Bellville 7520, South Africa  
T: +27 21 959 2955/2945 . F: +27 21 959 5170  
E: [pjosias@uwc.ac.za](mailto:pjosias@uwc.ac.za)  
[www.uwc.ac.za](http://www.uwc.ac.za)

A place of quality,  
a place to grow, from hope  
to action through knowledge

## Appendix 2: Information Sheet



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

*Tel: +27 21-959 3638, Fax: 27 21-959 2854*

**E-mail:** nlukelelo@uwc.ac.za

### **INFORMATION SHEET**

**Project Title:** Guidelines for social work interventions with children affected by HIV and AIDS

#### **What is this study about?**

This is a research project conducted by Nomvuyo Lukelelo from the department of social work at the University of the Western Cape. You are hereby invited to participate in this research project because the information provided will assist us in developing guidelines for social work intervention with children who are affected by HIV and AIDS.

#### **What will I be asked to do if I agree to participate?**

Depending on which stage of the research you participate in, you will be asked to participate in:

1. A workshop aimed at identifying and describing the intervention models used by social workers working with children affected by HIV and AIDS.
2. A workshop aimed at exploring the experiences of social workers using interventions with children affected by HIV and AIDS.
3. A Delphi study aimed at developing objectives for the design of the social work intervention with children affected by HIV and AIDS.

#### **Would my participation in this study be kept confidential?**

I will do my best to keep your personal information confidential. To help protect your confidentiality, all information gathered from this study will be kept in a locked filing cabinet. Your personal information will be kept anonymous. If a report or article is written about this research project, your identity will be protected to the maximum extent possible. If audio tapes are used, they will be kept in a locked cabinet and only the researcher will have access to it.

#### **What are the risks of this research?**



There are no known risks associated with participating in this research project. However, if you suffer any trauma or emotional distress resulting from this study, you will be referred for counselling to an appropriate resource

**What are the benefits of this research?**

This study is aimed at identifying best practice models for social work intervention in order to develop guidelines for social workers. It will inform and guide social work practitioners when working with children and families affected by HIV and AIDS so that effective and efficient services are rendered to those who need them.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized. Or lose any benefits to which you otherwise qualify.

**What if I have questions?**

If you have any questions about the research study itself, please contact: Nomvuyo Lukelelo at: Department of social work, Private Bag X17, Bellville, 7530: Tel: 021 959 3638 / Cell no: 076 494 7349 or email: [nlukelelo@uwc.ac.za](mailto:nlukelelo@uwc.ac.za)

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department of Social work:

Prof C. Schenck

University of the Western Cape

Private Bag X17

Bellville 7535

[cschenck@uwc.ac.za](mailto:cschenck@uwc.ac.za)

Dean of the Faculty of Community and Health Sciences:

Prof José Frantz

University of the Western Cape

Private Bag X17

Bellville 7535

[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

This research has been approved by the University of the Western Cape's Senate Research

Committee and Ethics Committee.

### Appendix 3: Questions for organisations



## UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

*Tel: +27 21-959 3638, Fax: 27 21-959 2854*

**E-mail:** [nlukelelo@uwc.ac.za](mailto:nlukelelo@uwc.ac.za)

### QUESTIONS FOR ORGANISATIONS

**Title of Research Project:** Guidelines for social work interventions with children affected by HIV and AIDS

1. Provide names of programs your organisation engages in with regard to children affected by HIV and AIDS
2. Describe the type of programs/interventions implemented by focusing on:
  - a. Aims and objectives
  - b. Who are the beneficiaries of the interventions/who are the interventions aimed at?
  - c. Who are the people responsible for implementing the intervention?
  - d. What are the roles of each of the people responsible for implementing the intervention?
3. What is the role of the social worker in the implementation of the programs?
4. Comment on the strengths of the programs/interventions
5. Comment on the gaps/weaknesses of the programs/interventions

#### Appendix 4: Consent form



## UNIVERSITY OF THE WESTERN CAPE

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Tel: +27 21-959 3638, Fax: 27 21-959 2854

E-mail: [nlukelelo@uwc.ac.za](mailto:nlukelelo@uwc.ac.za)

### CONSENT FORM

**Title of Research Project:** Guidelines for social work interventions with children affected by HIV and AIDS

The study has been described to me in language that I understand, and I freely and voluntarily agree to participate. My questions about the study have been answered.

I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

I agree to be audio-taped during my participation in this study	Yes	No
I agree to keep all information discussed during group discussions confidential	Yes	No
I agree to keep confidential information about other participants of this research	Yes	No

Participant's name: \_\_\_\_\_

Participant's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Name: Nomvuyo Lukelelo

University of the Western Cape

Private Bag X17, Belville 7535

Tel: 021 9593638/2277

Cell: 076 494 7349

Fax: (021)959 2854

E-mail: [nlukelelo@uwc.ac.za](mailto:nlukelelo@uwc.ac.za)

## Appendix 5: Interview Schedule



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 3638, Fax: 27 21-959 2854

E-mail: [nlukelelo@uwc.ac.za](mailto:nlukelelo@uwc.ac.za)

### INTERVIEW SCHEDULE

**Title of Research Project:** Guidelines for social work interventions with children affected by HIV and AIDS

#### SECTION A: BIOGRAPHICAL INFORMATION

1. Age

2. Sex

Male	<input type="checkbox"/>	Female	<input type="checkbox"/>
------	--------------------------	--------	--------------------------

3. Ethnic group

Black	<input type="checkbox"/>
White	<input type="checkbox"/>
Indian	<input type="checkbox"/>
Coloured	<input type="checkbox"/>
Other: please specify	<input type="text"/>

4. Home language \_\_\_\_\_

5. Type of organisation working for

Government	<input type="checkbox"/>
NGO	<input type="checkbox"/>
CBO	<input type="checkbox"/>
FBO	<input type="checkbox"/>

Other: please specify	
-----------------------	--

6. Highest qualification obtained \_\_\_\_\_
7. Number of years qualified as a social worker
8. Number of years working in current organisation
9. Number of years working with children affected by HIV and AIDS

**SECTION B : INTERVIEW SCHEDULE**

1. Describe the type of programs/interventions for children affected by HIV and AIDS implemented by your organisation
2. What is your role within the program?
3. What are your views regarding the intervention program in your organisation?
4. How would you describe your experience of the intervention program?
  - a. What are the positive experiences that you have encountered?
  - b. What are the challenges that you experienced?
5. Describe the kind of support available to you as a social worker to assist you in implementing the intervention programs for children affected by HIV and AIDS?
6. What do you think needs to happen differently to help social workers in implementing intervention programs for children affected by HIV and AIDS?



**Appendix 6: Correspondence from Journal 1**  
**Journal of Child and Adolescent Social Work**

Submission no: CASW-D-22-00260

Submission date: 07 October 2022

CASW-D-22-00260 - Submission Confirmation External Inbox x  

 **Child and Adolescent Social Work Journal (CASW)** <em@editorialmanager.com> 11:06 AM (5 hours ago)   

to me ▾

Dear Ms Lukelelo,

Thank you for submitting your manuscript, A systematic review of interventions used with children affected by HIV and AIDS in Africa for community-based care and support using a RE-AIM framework., to Child and Adolescent Social Work Journal.

The submission id is: CASW-D-22-00260  
Please refer to this number in any future correspondence.

During the review process, you can keep track of the status of your manuscript by accessing the journal's website.

Your username is: nlukelelo  
If you forgot your password, you can click the 'Send Login Details' link on the EM Login page at <https://www.editorialmanager.com/casw/>

Should you require any further assistance please feel free to e-mail the Editorial Office by clicking on "Contact Us" in the menu bar at the top of the screen.

With kind regards,  
Springer Journals Editorial Office



## Appendix 7: Correspondence from Journal 2

### Social Work/ Maatskaplike werk

Article submission number 1028:

Submission date: 05 August 2022



Dear author/s

Thank you for submitting a manuscript.

Please use the reference number, indicated in this email for future communication to the Journal.

The email address we used for this email is regarded as the corresponding author address for our communication. Please forward this email to your co-authors if applicable.

The manuscript will go through a double-blind review process, which may take up to six months. Thereafter, the Editorial Board will evaluate and consider the manuscript for publication. You will be informed by the Editor of the decision in due course.

Please note that since the journal is Open Access, an amount of R250.00 (tax included) per page is to be paid by authors, once the manuscript has been published and an invoice has been issued to you.

Your contribution is appreciated and we trust that your manuscript will be suitable for publication.

Best wishes

Prof Lambert K Fenzlbrecht

## Appendix 8: Correspondence from Journal 3

SAHARA-J: Journal of Social Aspects of HIV/AIDS

Submission ID: 220600175

Submission date: 20 August 2022

Date: Sat, Aug 20, 2022 at 3:16 AM

Subject: SAHARA-J: Journal of Social Aspects of HIV/AIDS - Manuscript ID 220600175

To: <nlukelelo@uwc.ac.za>

19-Aug-2022

Dear Dr Nomvuyo Lukelelo,

Your manuscript entitled "Implementation of interventions for children affected by HIV and AIDS in the Cape Town Metropole: perspectives from key role players" has been successfully submitted online and is presently being given full consideration for publication in SAHARA-J: Journal of Social Aspects of HIV/AIDS.

Your manuscript ID is 220600175.

All co-authors listed on the manuscript will also receive a copy of this email.

Please mention the above manuscript ID in all future correspondence or when calling the office for questions.

Submitting authors can view the status of the manuscript at any time by checking their Author Dashboard after logging in to <https://rp.tandfonline.com/dashboard/>. Please note that only submitting authors will be able to view the status of the manuscript from their Dashboard.

Thank you for submitting your manuscript to SAHARA-J: Journal of Social Aspects of HIV/AIDS.

Sincerely,

SAHARA-J: Journal of Social Aspects of HIV/AIDS Editorial Office

## Appendix 9: Editor Certificate



**CONFIRMATION OF EDITING: Nomvuyo Lukelelo**

**29 November 2022**

To whom it may concern

This letter serves to indicate that we at the Student Development Centre, reviewed and provided editorial feedback for the PhD Thesis of Ms. Nomvuyo Lukelelo. We have successfully done editing and formatting for over 50 postgraduate student theses, and attended various webinars on formatting and referencing.

We completed a language, format and referencing edit of the abovementioned author's thesis.

The nature of the editorial review was to provide feedback on:

- Sentence construction as it relates to the clarity of expression and style;
- Accuracy of grammar, tense related editing and punctuation;
- Harvard as it relates to both referencing (both in-text and full-citations) and format;
- Thesis format editing according to the typical thesis formats accepted.

Utilising the review functionality tools ('track-changes' and 'comments') in Microsoft Word, the author was requested to review and attend to changes that were deemed appropriate for the improvement of the text. The overall accuracy and quality of the document remains the author's responsibility.

Please do not hesitate to contact me should you have any further questions.

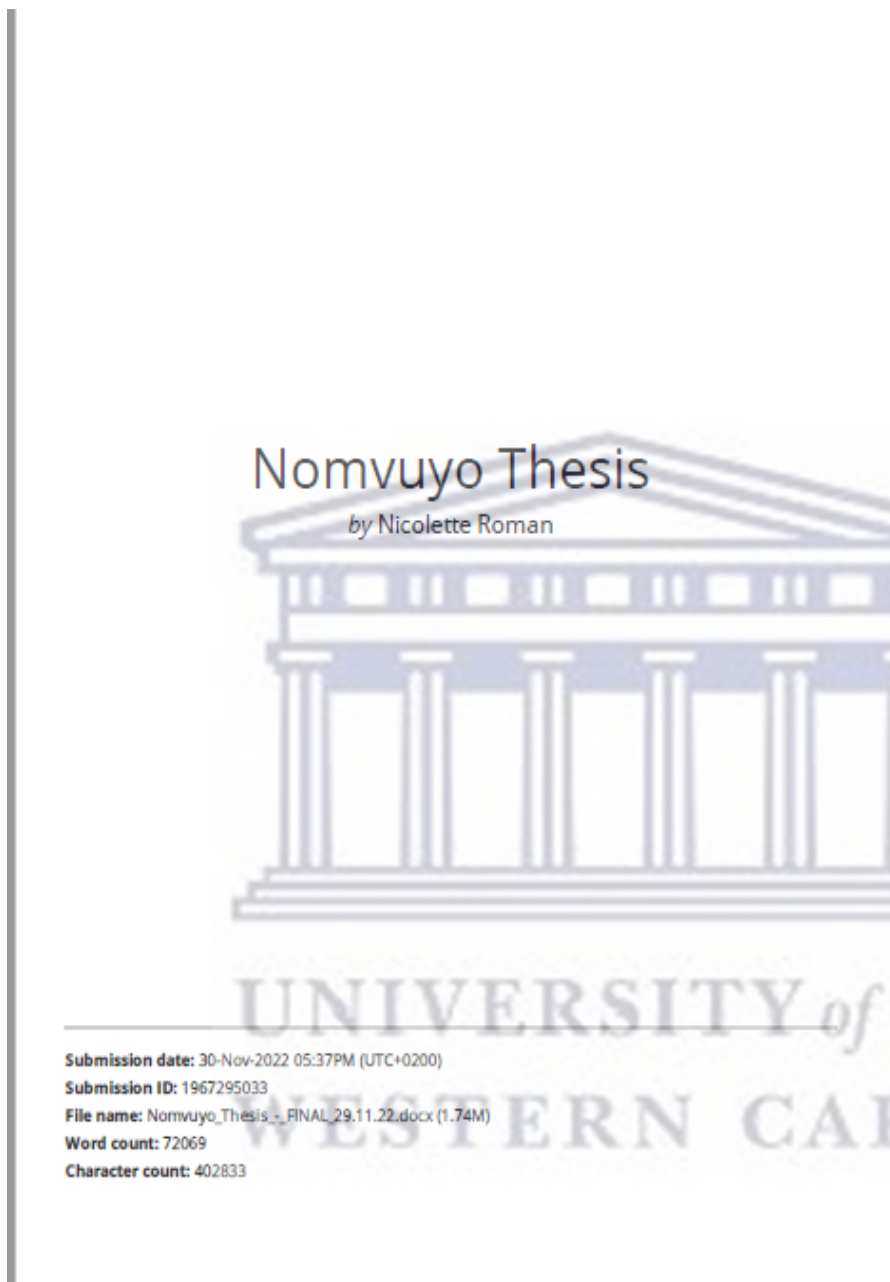
Warm Regards

Jill Masters

Director of Student Development Centre

[admin@studentdevelopmentcentre.com](mailto:admin@studentdevelopmentcentre.com)

## Appendix 10: Turnitin report





## Nomvuyo Thesis

### ORIGINALITY REPORT

<b>16%</b>	<b>12%</b>	<b>9%</b>	<b>6%</b>
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

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