PERCEPTIONS, EXPERIENCES AND COPING STRATEGIES OF FAMILIES CARING FOR CHILDREN WITH SPECIAL NEEDS WITHIN WESTERN CAPE COMMUNITIES

by

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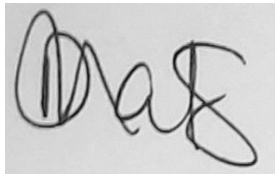
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PLAGIARISM DECLARATION

The research findings and outcomes of this research which envisaged to explore the experiences, perceptions and coping strategies applied by families caring for children with special needs. Is a product of my work, and relevant sources and scholarly views used in this research have been acknowledged.

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Signature Priscilla Matambanadzo

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ABSTRACT

The harsh economic environment, lack of adequate caregiving resources, lack of psychosocial support structures poses as some of the challenge's families caring for the children with special needs face. In exploring the experiences, perceptions and coping strategies applied by families caring for children with special needs care, the study sought to explore the (physical, social, psychological, emotional, financial) experiences of caring for a child with special needs and their experiences of access to services (healthcare, education, social). The caregiver's perceptions of family, service providers and community member's reactions towards their children with special needs and the coping strategies applied by families when caring for their child with special needs were also included in this study. The study was qualitative in nature and semi-structured interviews were employed. Participants were drawn from an organisation that assist parents with children that have special needs and all ethical clearance procedures were duly observed. Upon realizing data saturation from eight (8) participants out of the intended twelve (12) participants the researcher halted the data collection process paving way for thematic data analysis. The experience of caregivers, care givers access to services, perception towards children with special needs and the coping strategies by caregivers were the study's main themes. Using thematic data analysis, the study concludes that, regardless of context, colour and creed families caring for children with special needs find have difficulties in keeping up with the special needs of the child. The study unearthed that discrimination and prejudice of the disadvantaged was institutionalized and a thriving social norm. This was primarily due to the lack of knowledge in managing children with special needs. It becomes essential to provide for counselling services to the disabled children, the family members and communal interventions programmes where everyone is involved

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ABBREVIATIONS

GSDRC   Governance Social Development Humanitarian Conflict

ICF   International; Classification Functioning of Disability and Health

MDRC   Michigan Disability Rights Commission

DSD   Department of Social Development

WHO   World Health Organisation

UNICEF   United Nations Children Education Fund

Stats SA   Statistics South Africa

NCSNET   National Commission on Special Needs in Education and Training

NGO   Non-Governmental Organisation

SACSSP   South African Council for Social Service Professions

DEFINITION OF THE TERMS

Challenge: health, mental, social and economic issues impacting the day-to-day livelihood of children with special needs

Special needs: the individual requirements of a person with a disadvantaged background or a mental or physical disability (Oxford Dictionary, 1990).

Coping strategies: "are efforts, both behavioral and psychological, that people employ to master, tolerate, reduce or minimize stressful events" (Taylor, 1998).

Family: a family is a group of two or more people that are related by blood, marriage adoption, and step or fostering and who usually live in the same household (Australian Bureau of Statistics).

Caregivers: Caregivers in this thesis are informal caregivers. Informal caregivers, are are family members, or any other members who are deemed to be as part of the family unit (Bringham, 2017).
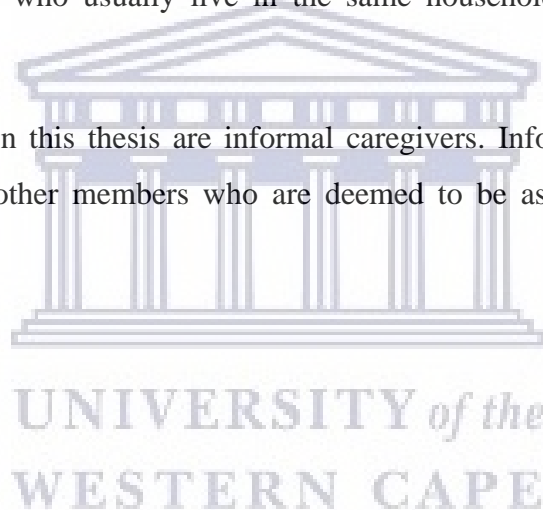
CHAPTER ONE
INTRODUCTION AND BACKGROUND

1.1   BACKGROUND

While acknowledging the work of (Kalman & Heller, 2015; Coetzee, 2016; Bringham, 2017; Thsitsake, Pengid & Peltzer, 2013) on children with special needs among other related work, this study envisaged to explore the caregivers experiences (physical, social, psychological, emotional, financial), perceptions and coping strategies in taking care of children with special needs. According to Thunderstone (2011), special needs can be defined as the requirements of children suffering from a wide range of disabilities and medical conditions. The requirements often range from psycho-social support, and assistance with feeding, and mobility that these children may not be able to attend on their own. Children with special needs have a high care demand as they often rely on their families to take care of them. As a result of the high care demand, families struggle to meet the caregiving demands (Geiger, 2012). According to Bringham (2017), caregivers of disabled children are prone to social discrimination and exclusion from the normal social setting of interaction due to stereotypes and belief systems on disability.

Kalman and Heller (2015) assert that social isolation emerged as an important issue confronting families with children with special needs,and this has a profound impact on their self-worth and self-esteem . As alluded above (Kalman & Heller, 2015; Keller, 2008; Thunderstone, 2011) a child with special needs is therefore not self-sustainable and needs a lot of extra care. This care surpasses the care that is usually provided to children by their families. Children with disabilities require constant attention and may never be left unsupervised which can be a daunting experience for families as this dependence could occur throughout the life of the child concerned. According to Keller (2008) living with a child with a disability can have profound effects on the entire family, parents, siblings and extended family members. In most families, children with special needs are often taken care of by family members. This could be parents, siblings or extended family depending on the family makeup. According to Taderera and Hall (2017), parents having a child with a disability may experience increased stress, which could affect their mental and physical health. Caring for special needs is a full-time job and can easily take up a lot of one's time without realizing it.

Keller (2008) added that "it may also be associated with guilt, blame, or reduced self-esteem." Coetzee (2016) notes that the responsibility of caring for children with special needs go beyond financial needs to impact on the inner family relatedness and has psychological effects on the being of the family. Accordingly, Geiger (2012) and Bringham (2017) assert that this may divert attention from other aspects of family functioning. Most of the child's requirements are often pricey as they are highly specialized and this does not make the burden of caring for a special needs' child any lighter or better, in fact it increases the stress on the family (Hashe, 2020). According to Bringham (2017) some of the challenges experienced by families with children with disabilities include effects for the quality of relationship between the parents and their living arrangements and future relationships and family structure. As caring for a child with special needs impacts greatly on the family, they would need support to assist or relieve them.

1.2   PROBLEM STATEMENT

South Africa faces an increased margin on inequality, rise in unemployment and an uncertain economic future due to volatile global markets. Consequently, these socio-economic challenges are blanket to most of the populace and certainly could be dire for children with special needs and their caregivers. People with disabilities in South Africa have been excluded from mainstream society (Bringham, 2017). The primacy of caregiving is often hinged on the patient or the child with special needs neglecting the caregivers. There is a lack of respite care to relieve family members caring for these children who need care and supervision 24 hours a day. Thsitsake et al. (2013) asserts that finding someone to watch their child for a few hours so they could have time for personal, marital, or family activities is documented as a universal challenge. This is congruent with Geiger (2012) who states that special skills are often needed to care for these children and concludes that, the typical child minder would not suffice. In addition, parents of these children are often criticized by their own extended family for not being able to better manage the behavior of their child with severe special needs. The frequent result is avoiding attending family and community events. Families caring for these children requested the need to have on-going support groups (Kalman & Heller, 2015). The experiences of families caring for these children could differ. Experiences could be based on previous experiences and on availability of social support. In the context of Mfuleni, where caregivers are unemployed women who are excluded from the mainstream economy, through exploring their perceptions, experiences and coping strategies of caregiving, the study questions whether

caregiving is gendered one. Departing from the known perceptions and experiences of caregivers around the world the study examines if these are the same with caregivers in Mfuleni.

1.2.1 Research question

The following are my research questions:

1) What are the experiences of caregivers caring for children with special needs?

2) What are the experiences of caregiver's access to services (healthcare, education, social care)?

3) What are the perceptions of caregivers regarding family, service providers and community member's reactions towards their children with special needs?

4) What are the coping strategies implemented by families with children with special needs?

1.3   AIM OF THE STUDY

The aimed at exploring the experiences, perceptions, and coping strategies applied by families caring for children with special needs.

1.4   OBJECTIVES

The specific objectives are:

1) To explore the (physical, social, psychological, emotional, financial) experiences of caring for a child with special needs.

2) To explore the experiences of access to services (healthcare, education, social care).

3) To explore perceptions of caregivers regarding family, service providers and community member's reactions towards their children with special needs.

4) To explore the coping strategies applied by families when caring for their child with special needs.
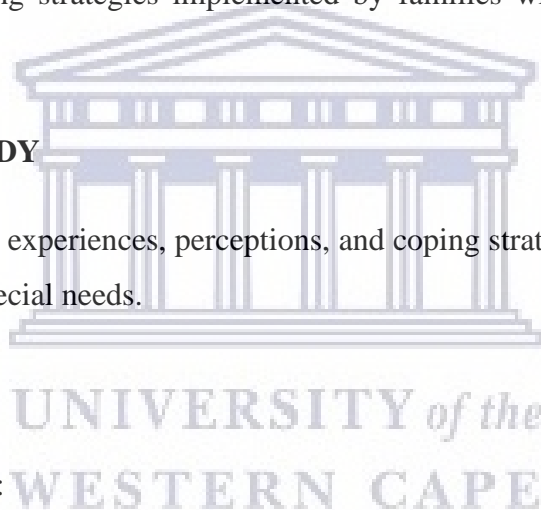
1.5   SIGNIFICANCE OF THE STUDY

The study outcomes will add to the already existing body of knowledge on caregiving for children with special needs in communities, psycho-social support, and financial needs for the caregivers. The study emphasizes the increased need for involvement of government and stakeholders in assisting families with children with special needs. Facilitating cohesion within the family could facilitate caring for a child with special needs.

1.6   CHAPTER OVERVIEW OF THE CHAPTERS

Chapter two of the study will provide literature review detailing the theoretical and conceptual framework on special needs caregiving and empirical studies done on the area of study pointing out literature gaps and challenges in context with the research area.

Chapter three of the study will usher the research design, research methods, the research conceptual framework, data collection and ethical considerations which were employed in the research process

Chapter four of the study provides for the study findings and discussion. Through thematic analysis of the findings, the researcher discusses the study findings with a critical engagement of the literature in chapter two of the study

Chapter five will usher the summary, recommendations and conclusion of the study.

CHAPTER TWO
LITERATURE REVIEW

2.1   INTRODUCTION

This chapter presents a review of literature regarding challenges (physical, social, psychological, emotional, financial, environmental)) experienced by caregivers of children with special needs as well as their coping strategies. Due to the limited literature published regarding this topic in Africa, most of the studies are international. A general background of information on disability which includes the definition, prevalence, its management, coping strategies, and challenges. The effects of disability on the family and the ability of caregivers to accept, cope and adapt to their children with special needs are equally presented.

2.2   Defining Disability

Disability, although a common term used in many scenarios, has often been defined through the charity, medical model, social model on disability, Human rights model, Interaction model. Defining disability in this part of the chapter becomes imperative as it determines the conceptual and methodological approach to the study and its outcomes and their analysis thereof. The United Nations Conventions on the Rights of Persons with Disabilities (2006) asserts that the concept of disability "is an evolving concept." Accordingly, Mitra (2006) cited in the Governance Social Development Humanitarian Rights Conflict asserts that there is no one single definition of disability. The GSDRC (2015) note the World Health Organization and the World Bank (2011) interpret the multiple definitions for disability to mean disability is not necessarily an individual attribute but an impairment defined by a less accommodating environment. As such the World Bank (2011) notes that the fact of one being impaired should not be translated to disability, on the contrary comprehensively less accessible and inclusive environments shape and construct the notions of disability. The consideration of the environment and how this impacts on people with impairments is therefore an important consideration when defining disability. Disability should therefore be considered The following chapter subsection will explore some of the known models of disability.

2.2.1 Medical Model

The Disability World (2017) notes that disability from the medical model is viewed as an individualized impairment that is as a result of disease, a health condition or a certain trauma which then calls for clinical treatment. Selignman and Darling (2007) notes that disability in the medical fraternity is viewed as illness. In the same vein Edmonds (2005) notes that children with disability in some circles are perceived to be as result of the lack of proper parental care, poor living social and economic standards that exposes one to malnutrition and unhygienic living conditions.

Conceding Edmonds (2005) line of thought is a reflection on the studies done on the causation of disability within Africa and Asia disabled children. The study purported that approximately two thirds of the cases of disabilities among children had been a result of war torn environments where children were subject to landmines, accidents and thereby sustaining injuries, the latter part of the study notes that the rise of congenital disease was a result of "malnutrition and micronutrient deficiencies" If disability is an individualized impairment and a form of illness as purported by the medical model, it therefore becomes imperative to unpack to what degree is disability individualized. The ACPF (2011) notes that health is expressed in three dimensions which are the body's function and structure level, the ability of the person to be active and engage in social economic and physical activities, and their participation in the society. Succinctly, Laws (2018) the medical model is perceived to be a normative one, thus classifying deviant or deficiency as disability.

2.2.2 Charity Model

Shanimon, Rateesh and Nair (2014) notes that the charity model views the disabled person as the "problem". As such they are dependent on society's sympathy and institutional support of survival and sustainability. Tsime (2014) purported the charity/tragedy model as depicting those disabled vulnerable, frail, weak and in need of pity. The depictions of the disabled populace are also used on multi-media platforms to further the need for donations and bankrolling of activities meant to help these so-called victims. Various schools of thought, including Tsime (2014)'s work criticize the charity model for enforcing labels and idealizing discrimination of disabled populace as victims and lacking capacity to fend for themselves or think as the normative people. As such the cause of the disabled has been included and branded in excluding terminologies like "special needs" physically incapable. The description of the

disability in relation to their condition other than person (Michigan Disability Rights Coalition, 2016).

2.2.3 Social Model

According to the MDRC (2016) disability through the lenses of the social model is defined as a result of the preconceived notions ferried within the social, environmental spaces and attitudinal barriers limiting populations with impairments to effectively participate in their societal activities. The ideology ferried in this model is likened to the notion of racism, like racism which the white population were found wanting various anthropological and political narratives, it is the racist populace that had to reconfigure their perception of other races.

As such the social model can be credited for placing the needs and cause for a sustainable livelihood for the impaired populations on the environment and society, motivating governments to craft policies that are synthetic to the cause of marginalized disabled populations (Tregaskis, 2010:13). According to the Disability and development Centre (2010:14-15) the social model can be summated as hinged upon the following conceptions:

> "It is based on the notion that society discriminates against the impaired societies. Disability is a social construct which emanates from a population failing to accommodate its populace. There is a need for structural and policy change to remedy the exclusion of impaired people. Disability cannot not be eradicated or prevented therefore it has to be embraced".

2.2.4 International Classification of Functioning, Disability and Health (ICF)

The ICF framework stands out as a synergy between the medical and social model, a framework conceptualized by the World Health Organization (2001) as an inclusive ideological standpoint in understanding and intervention on disability. It is therefore based on a biopsychosocial model of disability. The ICF framework offers three tenets in which disability is interpreted: the first one purports to the body these entails the body's function and structure, the second one speaks to the range of activities which the being performs or undertakes. The third one relates to the lived experiences in which the individual interacts with the environment, this pertains to access to infrastructure, coping with climate, their relationship with the society and family. The World Report on Disability by the World Health Organization (2011:262-263) noted that the disabled populace lacked adequate provision of services accessible by those not disabled this was primarily due to either the lack of policies for disabilities or proper enforcement of these

policies due to lack of funding and implementation strategies. In exploring the experiences, perceptions and coping strategies of families caring for children with special needs, the study adopts the ICF framework as its conceptual framework, primarily for its synergy of the medical and social model. While the study acknowledges the diagnosis of physiological challenges observed in children with special needs through the medical model, understanding the experiences and perceptions these families go through can be borrowed from the social model. To interpret these experiences, the input from the research forms as the primary data source and inferences have to be drawn from within the context of these experiences.

2.4 DISABILITY IN SOUTH AFRICA

Although there is general presumption that Southern Africa has a considerable number of disabled people, there is no direct pointers either to aggregate these perceptions by country or by any other demographic indices. Vergunst (2016) notes that it is inconsistent to compare Statistics South Africa census report on disability owing to the variability in methodological approach and conceptualization of disability in the census exercise done since 1996. However, recognizing the variegated results might help streamline and paint a picture on the existentiality of disability as a reality and a challenge to South Africa. According to Stats SA (2011) in 1996 an estimated 6.7% of the population was considered as disabled, this followed a baseline survey in 1998 which suggested that there was 5,9% of disabled populace, the 2001 census report purported that 5% of the population was disabled. According to Vergunst (2016) the South African 2011 census enforced the Washington Group Questions (these were a set of question profiling disability through the ICF framework) 7,5% of the population was disabled. The report findings suggested that females were more disabled than males from ages of 5 up to adulthood.

2.4.1 Children with disabilities in South Africa

The African Child Policy Forum, (A.C.P.F), (2011) notes that with the exception of white disabled children, the majority of marginalized children with disabilities lacked provision of better services and grew in abject poverty. This was also due to the socio-economic status of the care-givers and their controlled freedoms. According to the Department of Social Development, (D.S.D), (2009) although strides were made by the post-apartheid government to remedy and attend to the cause of vulnerable disabled children, the intervention of NGOs is more prevalent than frameworks and government policy on children with disability. The ACPF (2011) notes that despite Stats SA gazette on the disabled population in the census, there is

relatively inaccurate and inconsistent statistical evidence when it comes to the age of children and childhood gender specifications. Among other reasons these conflicts can be linked to, the lack of studies that employ screening and confirmation methodologies, use of different variables in studies which makes it difficult to offer a comparative assessment on disability numbers or any other outcomes. McLaren et al. (2004) notes that statistics on children's disability are marred in obscurity owing to the various definitions ascribed to disability given disability is a social construct.

2.4.2 Factors Contributing to Children Disability

Noting the WHO (2011), ACPF (2011) and Sangongo (2012) disability among children can be preventable among South Africa's populace. The Department of Social Development (2009) and DSD (2014) notes that an estimated 40% of disability cases and causes in South Africa can be preventable. Other enlisted factors contributing to disability is violence and crime, the lack of proper medical services or access to them, environmental factors, poverty, and caregivers' unhealthy lifestyle.

It is imperative to exemplify some of the known children's impairments prevalent in South Africa. Accordingly, UNICEF (2011) on South Africa children with disabilities is in sync with the ACPF in the classification of children with special needs or disabilities. Among other impairments prevalent within South Africa, is Developmental disability according to the work of MacLaren et al. (2004), Cerebral Palsy (CP), Couper (2002) and Sangongo (2012) notes CP as prevalent in South Africa as compared to other countries within Southern Africa. While down syndrome is often ascribed to increase with maternal age, UNICEF (2011) Kromberg (1997) notes that down syndrome is relative across all races in South Africa and its prevalence has little less to do with poverty or poor implementation of policies but more to physiological factors. Hearing impairments, Neural tube defects, intellectual impairments, attention deficit and epilepsy are considered to be among some of the impairments or disabilities prevalent in South Africa. According to Stats SA (2014), UNICEF (2017) there has been a paucity in research pointing to children living with disabilities. Arguably those statistics present besides the 2007 and 2009 baseline surveys different variables and methodologies were used which makes it difficult to offer credible statistical input.

2.4.3 Legislation and Policy on Disability in South Africa

The 1996 South African Constitution provides for equality and recognition of all South African citizens and observation of all human rights enshrined. However, this part of the chapter concerns policy and frameworks that are directly coined towards the cause of the disabled policy. Thus, the white paper on the Integrated National Disability Strategy, the National Disability Policy and the mandate of the National Commission on Special Needs in Education and Training will be summated for the purpose of bringing in the legislative context of this study.

2.4.3.1 *White Paper on an Integrated National Disability Strategy*

The Integrated National Disability (1997) was coined to speak to the cause of the people with disabilities. The strategy sought to address poverty affecting the disabled people and how they were excluded from poverty alleviation programmes, unemployment and the exclusion of the disabled persons, the strategy also sought to provide inclusivity of the disabled in all legislative issues. INDS among other issues discusses means to prevent disability where possible, rehabilitation of the disabled, and barriers to free access, education, the welfare and community development, employment of the disabled populace. The strategy also venerates on issues concerning housing, sport and recreation, transport, communication (Integrated National Disability Strategy, 1997).

2.4.3.2 *National Disability Policy*

The National Disability Policy is a policy tool meant to enhance the Department of Social Development legislative and implementation guideline when attending to the cause of the disabled. The policy aims to provide for guidance through developing and implementation of the department's policies, strategic framework and service delivery initiatives; to facilitate for the disabled people, access and provision to integrated social services; to inform and guide the department on prevailing barriers or limitations that exclude the disabled populace and advocate for the inclusion of the disabled in socio-economic sectors. The policy's objectives can be summated as to: integrate and mainstream disability across social development practices and into existing departmental policies, strategies and programmes that are aligned to departmental mandates; facilitate transformation shifts within the department and society regarding disability issues; define the role of social development in service provision to people with disabilities; facilitate development and implementation of an integrated and comprehensive social security

system; serve as overarching policy framework on disability within the department" (DSD, 2014).

2.4.3.3 *National Commission on Special Needs in Education and Training (NCSNET)*

The commission was established in 1997 and it sought to address the exclusion, structural discrimination and redress apartheid ills that had left the marginalized and disabled populace in abduct poverty. The NCSNET sought to provide for areas of exclusion of disabled children in the education sector, this would attend to issues of curriculum development, access to relevant study material and provision of user-friendly facilities for children with disabilities. The other objective would be to provide remedial action or improvements on the education training sector, this objective allowed for educators to be upskilled on the psychosocial demands of children with disabilities and acquaintance to better teaching aids. The NCSNET was also tasked with oversight on the enforcement of the constitutional resolutions on disabled populations.

2.4.4 Challenges with implementation of policies

The ACPF (2011), Du Plessis (2015) and Vergunst (2016) posit that the challenge in South Africa has not been about the policy congruence, but that of implementing the policy. Normatively this relates to the Stats SA (2011), UNICEF (2017) and WHO (2011) assertion that statistics on South Africa's disabled population are inconsistent and thus creating paucity in planning for interventions. As a result, the policy framework falls short of an informed accurate financial plan that directly speaks to the needs of the population.

Thus, in discussing the challenges in policy implementation two areas standout, defining disability and the distribution of resources to an inaccurate population. Defining disability in South Africa like any other part of Africa remains a contestation given the various negative subjective connotations attached to child disability. This bears an impact on how the child is assisted or even registered in the government departments as in need of aid. Boadi (2017), Graham, Moodley and Selipsky (2014) and Muderedzi, Eide, Braathen and Stray-Pedersen (2017) exhume the untold perceptions and classification that disability among children is often defined, described and how that influences the society engagement with the government to aid the children with special needs.

The paucity in accurate statistics in South Africa often threatens good governance and intervention mechanisms by the government and NGOs on the plight of disadvantaged or

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disabled children. This comes in handy due to the lack of studies on children living with disabilities and those present do not at most unpack the nature of disability as to kind the nature of intervention needed. As such this strain on the administrative component of interventions, budgets are often a misrepresentation of what is on the ground. The Fact Sheet (2017) on South Africa disabled people and the UNICEF (2017) illuminate variegated statistics and the vulnerability of the disabled due to inability of the government to allocate enough resources.

2.5 PERCEPTIONS, EXPERIENCES AND COPING STRATEGIES IN CAREGIVING

This part of the chapter provides for literature that outlines the perceptions, experiences of caregivers and their challenges likewise. As such the role of caregivers, the role of the family in care giving and accepting and adaptation are some of the themes to be discussed in this section. The latter part of this section will aggregate some of the known challenges of caregiving illumination empirical studies on the experiences of the caregivers.

2.5.1 Role of caregiver

To start with, the role of caregiver can be stretched to one who attends the socio-physiological and welfare needs of the children living with disability/special needs which can be summed to medical, personal and emotional needs. According to Kadungure (2017) the role of caregivers often varies depending on where they are working from asserting that home caregivers often have different responsibilities from foster home caregivers. Particularly due to the setting and resource availability. According Bringham (2017) there are different types of caregivers, these can be classified as formal and informal. Citing Coetzee (2016), Bringham (2017) asserts that formal caregivers can be teachers, nurses, social workers and or community workers, this group of caregivers is often remunerated and can be either trained to offer caregiving or not. The latter group speak to informal caregivers, these are family members, or any other members who are deemed to be as part of the family unit.

It becomes imperative for the caregiver to have a clear-cut comprehension of the child's special needs, the medical diagnosis and psychological technique and capacity to engage with the child. According to Bringham (2017) the caregiver's acquaintance to the child needs often to enable good rapport between the child and the caregiver often creating charisma and a strong personality in the child.

2.5.2   The role of the family in caregiving

According to the work of Opperman and Alant (2003), Hansan, Harty and Bornman (2016) studies show that children with disabilities who had siblings as their caregiver developed cognitive and speech skills a little earlier. This was primarily due to the sibling's positive attitude towards the child. Bringham (2017) however notes that despite the eagerness of siblings to support and care for their sibling with special needs, they had relatively low information on how to take care of them and what was required of them. This often-created distance between the siblings and parents and the child with special needs. The work of Vanegas and Abdelrahim (2016) posits that normatively and regardless of the knowledge to take care of their disabled sibling, siblings form part of the family unit that is often intimate and support the family in the welfare and psychological development.

The work of Kadungure (2017), Tancred and Greeff (2015) and Ebrahim and Muthukrishna (2014) points to the involvement of women and parenting of children with special needs as compared to the role fathers play. Research done in other studies often point the burden of parenting a child on mothers and less known about the fathers. According to Bringham (2017) recruitment of participants in studies focusing on children with disabilities women tended to participate more or doubled the number of fathers in the research study.

Hashe (2020) examined strategies of parents to ensure the health and well being of children with disabilities. The study notes that essential to parents being able to ensure the health of their disabled children was their capability to express and communicate their emotions regardless of the limiting cultural connotations of disability. Citing Fernández, Carrera, Sánchez Fernández, Paez & Candia, (2000), emotional expressiveness of caregivers or parents was often controlled by the social environment and power dynamics in marital relationships. In Hashe (2020)'s study, women interviewed in the study felt the possibility of being misunderstood with their partners/ husbands if they were to express their emotions. In understanding the role of the family in caregiving, it becomes imperative to note the room for emotional expressiveness can be instrumental in contributing to the health and wellbeing of the caregiver and becomes empowering in their ability to provide care for the disabled child.

The family as a unit can be instrumental in the rehabilitation and psycho-social support of both the disabled child and the caregiver, on the other end the lack of family support can be detrimental and create a series of repercussions on mental and emotional health of the caregiver

and disabled child. Thoya (2017), conducted a study on the experiences of parents rehabilitating children with Cerebral Palsy in Khayelitsha, a low income township in Cape Town. Cerebral Palsy as a form of disability incapacitates one to function normally affecting perception, cognition, muscle movement and sensation among others bodily limitations. The lack of support from family members, stigma from society, marital challenges presented as challenges faced by some of the participants. The inability of families to understand Cerebral Palsy and the social strain that comes in with dealing with Cerebral Palsy often lead some family members to negate their children, disassociate with caregivers and deny any responsibility often living the caregiver often the women with the burden to take care of the child.

2.6 CHALLENGES EXPERIENCED BY CAREGIVERS OF CHILDREN WITH SPECIAL NEEDS

Bringham (2017) expounds on the perception of caregivers and their challenges on caregiving. In ascertaining the caregiver's feelings and perceptions on "how it feels for caregiver to care" Bringham (2017) manages to syphon the underlying challenges faced by caregivers and how they conceptualize these in their everyday routine of caregiving. This part of the chapter presents some of the challenges that a caregiver goes through. These are psychological challenges, Socio-economic challenges and environmental challenges respectively.

2.6.1 Psychological challenges

Various research studies report that caregivers, as a result of their responsibilities, are stressed and at times distressed. The work of Thsitsake et al. (2013) that sought to understand the perceptions of caregivers on taking care of children with special needs established that the majority of them were stressed. Coetzee (2016) notes that caregivers in South Africa experienced ``additional stressors'' and this was due to the lack of resources. Bringham (2017) notes that children with behavioral challenges, physical disability often posed as a challenge to care givers hence they were likely to stress.

Geiger (2012) notes that caregivers needed to feel supported by other family members as they reported feeling lonely, unattended to and not appreciated for the role they play. As noted in Kittay (2005) majority of the women voiced their strain and stress in taking care of the children with less care or attention from the father. The lack of knowledge in caregiving often results in

caregivers feeling "anxious, worried and fearful". Mhaule and Ntswane (2008) assert that caregivers were fearful of mentally challenged children who often exhibited violent behavioral traits. The existing fact that these children might pause as a threat or cause substantial harm to others kept the caregivers at bay, often worried and fearful.

2.6.2   Financial Challenges

McNally and Mannan (2013) assert that children with special needs often require an additional budget for their upkeep. The additional financial needs in education, health and upkeep often weigh on the budget of most families and to some extent exacerbates the already existing financial challenges. Although various countries in Southern Africa provide disability grants to assist caregivers. Studies done have shown that the disability grant often does not meet the basic requirements of these children's monthly needs (Oti-Boadi, 2017; McNally & Mannan, 2013; Taderera & Hall, 2017).

Olsson and Hwang (2006) note that mothers with children with special needs often have lower employment levels as compared to their counterparts with able bodied children. In some instances, the primary caregivers who are often biological mothers drop out of work or cannot commit to demanding work schedules as a result of the primary caregiving role. As noted by Ndadzungira (2016), primary caregivers with no form of employment find themselves isolated, stressed as a result of financial constraints. Although other family members might have the required financial muscle to assist primary caregivers, stereotypes, superstitions and traditional belief systems discourage them from doing so.

2.6.3   Social Challenges

Community support structures in assisting children with special needs goes a long way in improving the livelihoods of children with special needs and contributes to the emotional wellbeing of caregivers. Bayat (2007) notes that in fear of being roped in the stigmatisation and discrimination that their relatives with a child who has special need are in, family members often shy away and dot support the neither the child nor the primary caregiver. Discrimination and stigmatisation of the disabled and the biological mothers are often a derived from cultural and religious belief systems. Bayat (2007) asserts that religious systems often associate disability with evil spirits or curses from the gods or God. Thus, disability is distanced from any biological deficiencies to represent a punishment from the supreme deity. The consequences of such stereotypes and belief systems often concretise discrimination of the

disabled and isolating the mother of the child and the child. Harper (2013) notes that in some instances due to these stereotypes, marriages collapse, and the mother and child are sent off.

2.6.4   Environmental Challenges

Disability is a condition that limits mobility, lessens vision or aural acuity, reduces stamina and inhibits a person's ability to manipulate the environment with a minimal degree of effort (WHO, 2006). Accordingly, physical environmental barriers are those aspects of the built environment which lessens access for a child or anyone with a disability (Lollar, 2008). These may include parts of buildings, landscapes, walkways, parking areas, high curbs, lack of ramps, narrow sidewalks, heavy doors etc. (Bodde, 2009). The ability to move safely and independently, referred to as mobility, is a fundamental part of basic activities of daily living of human beings. One of the neurological consequences of cerebral palsy is the limitation in mobility that leads to dependency.

2.7   EMPIRICAL STUDIES ON PERCEPTIONS OF CARE-GIVING

Using semi-structured interviews to understand the lived experiences of Iranian mothers with children with learning disabilities. Kermanshahi, Vanaki, Ahmadi, Kazemnejad and Azadfalah (2008) on their findings draw on two themes "being the center of stress circles and in the midst of strength" The study notes the emotional exhaustion that comes with mothering a child with learning disabilities and how social conceptions and expectations of motherhood often pressure mothers as primary caregivers.

Jack (2016) explored parent experiences and coping strategies in raising children with Asperger syndrome which is classified as an autism spectrum disorder in New Zealand. The study employed semi-structured interviews and data were interpreted using the family resilience framework. Four themes were identified and these entailed, the lack of acceptance and understanding of autism in the community which led to stigmatisation; costly medical diagnostics processes that were recurrent; increased tension between families, and social skill difficulties among those with autism. The study has been widely used in contributing to the theoretical construct of resilience. Cauda-Laufer (2017) conducted a study to investigate the caregiver of a parent's coping mechanisms' when upbringing a child with disability. The study also sought to ascertain whether positive or adaptive coping determined improved mental health. Using questionnaires as the research instrument, the study findings indicated that there

was no significant relationship between coping mechanisms and distress. Positive coping strategies did not ultimately lead to improved or better mental health for the caregiver or parents. The study recommends the need to strengthen social support, increased awareness of children with disability, education and health care support for children with Asperger syndrome.

In exploring the perceptions and treatment of children who lived with cerebral palsy among the Tonga people in Binga Zimbabwe, Muderedzi et al. (2017) employed a longitudinal study. Using in-depth interviews, ethnographic studies, focus group discussions, and participant observations. The study findings conclude that historical background, life experiences, social and cultural factors contributed in the mapping of stereotypes and treatment of the children with cerebral palsy. The study recommends involvement from government and civil organisations in improving the livelihood of the children and caregivers.

In Kenya, Gona, Mung'ala-Odera, Newton and Hartley (2010) conducted on the challenges and coping mechanisms of caregivers while caring for children with disabilities. The research employed unstructured observations and in-depth interviews and data was analyzed and stored in Nvivo software. The findings of the study indicated that the arrival of a child with disability "severely impairs the expectations' they find themselves, anxious about the future of the child and theirs, they find themselves on society's onslaught and labeling. The study recommends that the known experiences should be used in preparing social support structures for caregivers.

Taderera and Hall (2017)'s research focused on the challenges faced by parents with children who had learning disabilities in Opuwo Namibia. Data drawn from semi-structured interviews was analyzed using thematic analysis. The research outcomes conveyed the significant gaps in knowledge of learning disabilities among parents. As such parents did not have an awareness of policies and other forms of interventions that were at their disposal to assist their children with learning disabilities. The study results also indicated that single parents struggled to take care of their children as they were mostly unemployed which made life difficult for their children with learning disabilities. The study recommends the need for improved policy implementation on children with learning disabilities.

2.8   CHAPTER SUMMARY

The chapter has presented the theoretical conceptions of disability, the known legislative frameworks and the role of caregivers and their challenges. The lack of empirical studies on the actual needs and number of children with disabilities stand as a limitation to government intervention mechanisms. The chapter has shown that while there have been models to try and define disability, the lack of a clear-cut definition of disability still hinders statistical efforts. Although the policy framework in South Africa seems to attend to the cause of the disabled, they are not fully implemented primarily due to the lack of resources. The study through exhuming the challenges of caregivers drawn from various studies has shown that caregivers in South Africa lack proper training, are less resourced and need the intervention of the government to equip them in caregiving and counseling. The chapter has also shown that the family as a unit still stands formidable to offer informal care giving to the children. The chapter has shown cognitive development as quicker when the family members are involved in caregiving.

CHAPTER THREE
METHODOLOGY

3.1   CHAPTER INTRODUCTION

This chapter discusses the methodology used in this study. The discussion covers the research setting and design, sample and sampling procedures, data collection procedure, data analysis and ethical considerations.

3.2   RESEARCH SETTING

The research was conducted within the Western Cape, a province in South Africa with a 6% disability rate according to the census that was conducted in 2011. Cape Town has an estimated population of 3,7 million people with Asians making up 1%, white 15%, and black 38% and colored 47% (Stats SA, 2011; City of Cape Town, 2010). The researcher chose participants from Mfuleni. Mfuleni is resident to informal workers who live in informal and formal but substandard settlements (Hungry Cities, 2017). According to Stats SA (2011) 77% of the households in Mfuleni have a monthly income of ZAR 3200. 00 or less suggesting that Mfuleni is a low income township. Although residents in Mfuleni have access to electricity, water, flushing toilets, and public hospitals, the Stats SA 2011 census suggest that there is a relatively low labour intake, suggesting the rate of employment is higher estimated to be at 39.74% using the controlled definition. Participants in the research study were purposely sampled from Uhambo Foundation, an organisation that operates within Mfuleni. Uhambo Foundation is a non-profit organisation that seeks to capacitate and empower disabled children particularly from low income households. This setting was chosen as it was accessible to the researcher, hence it was a setting of convenience. It can be seen as representative of the townships in the metropole region of the Western Cape.

3.3   Research Design

A descriptive (qualitative) research design was used in this study. Babbie (1998:92) describes a descriptive research design as a major purpose of many social scientific studies to describe situations and events. This design was therefore appropriate as it provided experiences of families caring for children with special needs in local community's information which is

limited in the literature. In this, raising a child is a very personal experience. Families caring for children with special needs, in this instance, would have first-hand knowledge regarding the challenges, perceptions and coping strategies. Babbie and Mouton (2010) assert that a qualitative research approach is used when the researcher wants to understand the research topic according to the participants' frame of reference. It entails how people attach meaning to emotions and remarkable developments in their lives. It is an approach where the researcher learns a lot from the participants and contrary to popular belief, the participants were the experts and for the research to yield results the researcher was more of a facilitator than an expert. For the aforementioned reasons, the researcher found qualitative research to be the ideal research approach.

The researcher also wanted to understand the perspective of the participants and explore their coping strategies. Qualitative research was suitable and ideal for this particular study as the researcher needed first-hand information from families caring for special needs about their experiences and challenges faced in various settings during care times. Ritchie and Lewis (2003) assert that "qualitative research should be used when the phenomenon being studied is deeply rooted within the participants personal knowledge or understanding of themselves". Interviews were conducted that were guided by an interview schedule..

3.4   STUDY POPULATION AND SAMPLING

Marlow (1998:134) explains population as the sum of all possible cases that the researcher is ultimately interested in studying. Terre Blanche, Durrheim and Painter (2006:49) defines sampling as the selection of research participants from an entire population and involves decisions about which people, settings, behaviors and social processes to observe.

3.4.1   Sampling Procedure

Research participants are chosen through a process called sampling. There are many types of sampling and Marshall (1996:523-524) identifies three sampling techniques. These are convenience sampling, purposive sampling and theoretical sampling. Due to the nature of the study the researcher employed purposive sampling. Purposive sampling can be defined as the sample whereby the researcher uses his or her own judgement and handpicks participants from a target population for inclusion in the study based on criteria for inclusion. Using purposive sampling, the researcher actively seeks out and selects those participants who are information

rich and informed and possess first-hand experience of the culture, social process, or phenomenon the researcher wants to investigate and who will be best suited to answer the question says (Alpaslan, 2005).

The researcher purposively selected the sample according to the above-mentioned diagnosis of the child with special needs from a list of the names of the clients that were provided by the Uhambo organisation. For a participant to be included in this research project they had to be caring for a child with special needs. The child could have either a physical or intellectual disability.

3.4.2   Sample Size

The size of the sample was controlled by saturation of information, which means the point at which repetition or confirmation of previously collected data occurs, thus there will be no specific number of participants (Streubert-Speziale & Carpenter 2003:25). Eight (8) participants were interviewed as a result of data saturation.

3.5   DATA COLLECTION

3.5.1   Data collection methods

According to Kvale (1996:174) an interview is "a conversation, whose purpose is to gather descriptions of the life world of the interviewee "during the interview the researcher and the interviewee engage in an interview. The researcher made use of an interview guide so as to explore the unique views of the participants. An interview can be defined as a conversation with purpose where the individual's perspective of the concept is explored (Alpaslan, 2010; Tutty et al, 2001). Furthermore, according to Green and Thorogood (2009:285), "an in-depth interview or qualitative research interview aims to allow the participant to speak at length, in detail, in ways in which he is most comfortable, on a given topic". In this, the researcher allowed the families and careers to express themselves fully on their experiences, challenges and coping strategies.

An interview guide provides the researcher with a set of predetermined questions that might be used as an appropriate instrument to engage the participant and designated terrain. In this research study the researcher compiled a subset of questions which were related to the experiences, challenges and coping strategies of families caring for children with special needs.

The researcher especially used unstructured interviews in order to explore with the participants their experiences, challenges, views, perceptions, ideas, beliefs and coping strategies. The method was much more flexible for the researcher and participants. The researcher made use of a set of predetermined questions contained in an interview guide. However, the interview was guided, rather than dictated by the schedule.

To participate is to take part and to observe is to pay close attention to detail. According to De Vos, Strydom, Fouche and Delport (2011:335) "in participant observation, the gathering of data boils down to the actual observation and the taking of field notes". Adding to this statement Fossey, Harvey, Mokhtari and Meadows (2016) say that "interviewing, focus-group interviews and participant observation are common modes of qualitative data gathering". An interview is a discussion that is held for the purpose of evaluation for whatever reason. In this research the researcher used semi structured interviews facilitated by open-ended questions contained in an interview guide. According to Alpaslan (2010:23), with structured observation the researcher may employ a set of questions to guide him/her. The researcher used a letter requesting participants' participation in the research project and completed an informed consent form. The researcher prepared the participants to be ready for what is expected from them as participants. The researcher informed the participants the nature and the purpose of the research study since they have personal experiences in as far as caring for children with special needs is concerned.

Creswell (2007:54) adds that "in a narrative study, one needs to find one or more individuals who are accessible, willing to provide the information and distinctive for their accomplishments and ordinariness or who shed light on a specific phenomenon or issue being explored.

In accordance with the stipulations contained in Alpaslan (2010:34), the researcher used open ended questions as this allowed the participants to talk openly, tried not to interrupt participants too often when they spoke and tried to get as much detail as possible from each question.

3.5.2 Data collection procedure

Once the ethical clearance and the necessary permission were obtained, the researcher approached the Social Worker from Uhambo foundation and asked for their client database. The Uhambo foundation was used as a starting point for accessing participants for the study. The researcher was invited to the Uhambo foundation and met their management. The Uhambo foundation provides services to parents of children with special needs, namely children who need assistance from a caregiver to complete activities of daily living. so this made it very easy

for the researcher to select participants. The researcher was informed about management of information and social work ethics by the Social Worker. The community development worker who is also a parent of a child with special needs was enlisted among the potential participants. From then on, the participants were approached telephonically and in person by the researcher with the help of the community development worker. The community development worker negotiated entry for the researcher in Mfuleni inviting them to be part of the study. The recruitment process took about 2-3 weeks. Once all the participants were recruited, they were invited for an interview at a place and time that was suitable for them. All the interviews were conducted at the Mfuleni Library.

The participants were prepared for data collection by being given an idea of what sort of questions to expect in the interview. According to (Rogers & Bouey, cited in Alpaslan, 2010:33) the important actions to be taken in preparing participants for participation in research projects are discussed in the following paragraph:

The researcher informed the participants about who she was and how the researcher got their name. The onus was also on the researcher to explain to the participants why the researcher wanted them in particular to participate in the study as well as elaborate on the inclusion and exclusion criteria. The researcher then explained to them what will be asked of them as well as where they would like the interviews to take place. The researcher informed all the participants that the interviews would take about 30 to 45 minutes. The researcher also asked them for permission to audio tape the interview so that the researcher can focus her undivided attention on them, and that the researcher did not want to lose the important information that they shared with her. The participants agreed and so the respective interviews were recorded. The researcher used an audio tape recorder for this purpose. The researcher informed them that after the interview she will write the interview on the tape over onto paper and that she will disguise all the information that could identify them. Issues of confidentiality and management of information and the research findings were also discussed. All the participants agreed and so the data collection began. The researcher made use of two local languages Xhosa and Afrikaans. Upon completion the researcher thanked all her participants for their time and information they shared with her. Data was collected during October 2017.

3.6   METHOD OF DATA ANALYSIS

To analyze is to examine in order to discover and a method is a systematically planned way of doing things. Babbie, as cited in Alpaslan (2010:25) states that "qualitative analysis is a non-numerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships". Gibbs (2007:1) adds to this statement that "the idea of analysis implies some kind of transformation as you start with collection of qualitative data and then process it, through analytic procedures into clear understandable analysis. Themes drawn from the research were inductively drawn from the research findings.

Creswell (2007:150-155) mentions that "the process of data analysis and interpretation can best be represented by a spiral image. The researcher moves in analytic circles rather than using a fixed linear approach". Creswell as cited in Huberman and Mile (1994) adds that "data analysis is not off the shelf, rather it is custom built, revised and choreographed".

The data the researcher used in this study was analyzed according to the eight steps of qualitative data analysis in Creswell and cited by Alpaslan (2010:25-26). The researcher assigned researchers assistants to transcribe the audio-taped interviews verbatim and translated it to English. Once this was completed she read through all the transcripts to get a sense of the whole picture. She read through all the transcripts carefully and made notes of ideas that came to mind. As a start the researcher selected one transcribed interview which she read through it, asking herself what it was about. She did not think about the "substance" or content of the information, but about its underlying meaning. The researcher then wrote down her thoughts in the margin.

When she had completed this task for several interviews, the researcher made a list of all the themes. She put similar themes together and listed these topics in columns that might be headed "major topic, unique topics" and "leftovers". She then found an appropriate abbreviation for each of the identified topics and the most descriptive wording for the topics and collated them into categories. She made a decision on the abbreviation for each of these categories and then identified codes.

The researcher took notes during the interviews with the knowledge and consent of the participants. The researcher also sketched ideas and summarized field notes which were then inductively inferred into building emerging themes. The thesis supervisor was engaged during the data collection process.

3.7 ETHICS

Ethics are the principles of right or wrong as stated by the South African Council for Social Service Professions, SACSSP. It is all about values, morals and can even be seen as a code of conduct to some extent. Ethics is conforming to the standards of conduct of a given profession or group. According to Neumann (2011:90) every researcher should be ethically sound in order to protect participants from any physical or psychological harm and treat participants with respect and dignity. Baker (2003:106) in the social work dictionary defines ethics as "A system of moral principles and perceptions about right versus wrong and the resulting philosophy of conduct that is practiced by an individual, group, profession or culture".

Data collection commenced after ethics was received from the Humanities and Social Science Research Ethics Committee at the University of the Western Cape (HS/16/7/11) (Appendix E). Before the researcher proceeded with the process of data collection, she made sure that her participants voluntarily consent and willingly participated in her research project. As the researcher was interviewing with an interpreter, she made sure that the interpreter understood the importance of informed consent, anonymity and confidentiality and management of information before embarking on the project. The participants were informed that their participation in this research is completely voluntary. The participants were not forced in any way to take part in this research project. Their decision to participate, or not to participate would not affect them in any way now or in the near future. The participants were also told that they could change their minds anytime during the study and to withdraw from the study. The participants were informed that they could ask questions about the study at any time. If needed they would be referred to a relevant healthcare provider. The researcher implored design suitability which according to Lincoln and Cuba (2000) and Fraenkel and Wallen (2003:158) whether the methods of a study were appropriate for answering the research question and is concerned with consistency and procedures of usefulness.

3.7.1 Trustworthiness

3.7.1.1 *Transferability*

In defining transferability, Polit and Beck (2014) assert that it refers to the extent to which the research results are useful to other research settings and is comparable to generalisation in quantitative research. The study's theoretical and methodological approach were comprehensive making them useful and comparable in other research settings.

3.7.1.2   Credibility

Credibility concerns the confidence in the truthfulness of the study or research findings and the concept is analogous to the quantitative research internal validity (Shenton, 2004). The researcher ensured credibility by conducting the study using the standard procedures usually utilised in the designated qualitative approach. In order to establish credibility, participants were continuously engaged.

3.7.1.3   Dependability

According to Shenton (2004), dependability refers to how stable the data is over time as well as over the study conditions and is analogous to reliability in quantitative research. To ensure dependability the researcher maintained an audit trail of all process logs, that is, researcher notes of every activity that happened during the research period as well as all decisions concerning the study like participants interviewed and participant observations.

3.7.1.4   Confirmability

According to Shenton (2004), confirmability refers to the impartiality or the extent to which results are replicable or consistent and are corresponding to objectivity in quantitative research. Detailed notes of all decisions and analysis were kept as the research progressed. The researcher conducted member-checking with the research participants to ensure confirmability.

3.7.2   Bracketing

In order to ensure that the findings of the study were based on responses from the participants, the researcher applied the bracketing technique. In doing so the researcher was able to view the data objectively and refrained from allowing personal biases to influence the research process. The researcher consulted her supervisor about the findings and together they concurred that the data supported the themes, ensuring that the quotations also aligned with the themes.

3.7.3   Informed consent

During the interview the researcher discovered that the families caring for children with special needs volunteered a lot of information regarding the challenges they were facing, coping strategies employed and their perceptions. According to Yegidis and Weinbach (2002) "informed consent aims to protect the participants from unknowingly getting themselves into a

situation from which they wish to withdraw once the research process has started. This was achieved through advising participants in advance that all that was to be discussed would be kept confidential. The researcher also asked participants for consent to share any research results with supervisors or any other relevant people for academic purposes, to which they agreed.

3.7.4   Anonymity/ confidentiality

When something is anonymous it is said to lack marked individuality or singling out. The researcher had a pre-briefing with the relevant careers for children with special needs in which confidentiality and all the terms and conditions of the research project were discussed. The researcher did this in order to make sure that participants are fully aware of the ethical considerations.

Anonymity means that no one, including the researcher, should be able to identify any research subject afterwards (Strydom in De Vos et al., 2005:62). The researcher will make use pseudo names so as to ensure confidentiality. The information gathered will only be accessed by the researcher and other academic staff. The researcher also informed the participants about their rights and so they are aware of it. Participants will also have access to the audio tapes if they so wish.

3.7.5   Ensuring confidentiality of data

Management of information is to ensure that the information obtained during the research is taken care of and does not end up in the wrong hands. It entails taking charge as well as responsibility and accountability from the researchers' part. In the beginning the participants were concerned about their neighbours knowing about their private life but the researcher assured them she was governed by a code of ethics where she is not allowed to discuss any such conversations with anyone, except her supervisor. The participants were told that the interview, tapes, notes, and scripts will be kept in a locker and that the researcher would make use of pseudo names. Management of information also includes self-reflection on the part of the researcher. The researcher needs to look closely at her role as the researcher and what could be done differently.
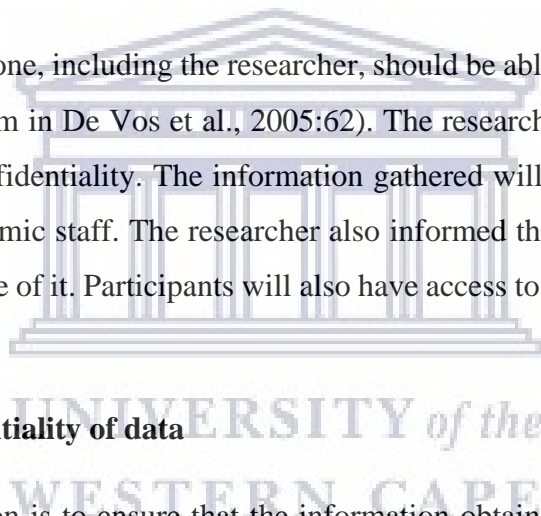
CHAPTER FOUR
FINDINGS AND DISCUSSION

4.1   CHAPTER INTRODUCTION

The research study sought to explore the experiences, perceptions and coping strategies applied by family members caring for children with special needs. To attend to the research aim, five objectives were set and these entails: (1) explore the (social, psychological, emotional, financial) experiences of caring for a child with special needs; (2) to explore the experiences of access to services (healthcare, education, social care); (3) to explore perceptions of caregivers regarding family, service providers and community member's reactions towards their children with special needs; (4) to explore the coping strategies applied by families when caring for their child with special needs.

This chapter will present the findings of the study and offer an informed thematic discussion congruent to the objectives of the study. Demographics of the study participants will be the point of departure and then a detailed thematic presentation of the study findings and discussion. Themes to be discussed will explore the experiences of the caregivers, their access to services such as health and education, and the

perceptions of children with special needs by their families and community. The later part of the chapter will discuss the coping strategies that were adopted by caregivers.

4.2   DEMOGRAPHICS

Table.1 below shows participant demographics, the table shows that all participants interviewed were primary caregiver or biological mothers of the disabled child. Cerebral Palsy, Autism and Traumatic brain injury were the special needs of the children whose caregivers were interviewed. Participant age groups ranged between twenty-eight (28) to thirty-nine (39) years and all the interviewed participants were unemployed females and were mothers of the children.

Table 4.1:   Participant Demographics

Participants Name/Alias	Age	Gender	Location	Employment status	Nature of special needs	Relationship with Child
Participant A	30	Female	Mfuleni	Unemployed	Cerebral Palsy	Mother
Participant B	29	Female	Mfuleni	Unemployed	Cerebral Palsy	Mother
Participant C	39	Female	Mfuleni	Unemployed	Cerebral Palsy	Mother
Participant D	32	Female	Mfuleni	Unemployed	Cerebral Palsy	Mother
Participant E	28	Female	Mfuleni	Unemployed	Autism	Mother
Participant F	33	Female	Mfuleni	Unemployed	Autism	Mother
Participant H	36	Female	Mfuleni	Unemployed	Traumatic Brain Injury	Mother
Participant G	38	Female	Mfuleni	Unemployed	Cerebral Palsy	Mother

4.3   PRESENTATION AND DISCUSSION OF FINDINGS

This study provides themes drawn inductively from the participant input while calibrating them with the research objectives. As such each objectives' finding will be presented followed by a discussion drawn from emerging themes from the data findings. The discussion draws from the research findings and literature on the same theme of discussion. Four objectives will be discussed, namely the experience of caregivers; access to services; perceptions of community and family towards children with special needs; and caregivers coping strategies.

4.3.1   Experiences of Caregivers

The first objective of the study sought to explore the social, psychological, emotional and financial experience of caregivers for children with special needs. Unemployment due to spending more time attending to the child, the disabled child's health, marital uncertainty, absent father and financial challenges were noted as arising themes. The table below presents the schematic findings of the study, codes were drawn from the notable participant input and

themes were created. Themes created will be used henceforth to discuss the findings of the study against known literature.

Table 4.2: Experiences of Caregivers

What are the experiences caring for children with special needs		
Codes	**Notable Participant Input**	**Emerging Theme**
Cannot look for employment Struggle to keep employment	Participant A *"difficult to be the mother of the child with a disability as you are stagnant as you cannot look for employment since you are the parent of a child with a disability."*	Unemployment
Doubt and anxiety on future of marriage Financial challenges causing despondency in the family	Participant D*, "I also think of the future. What if my husband leaves us? How are we going to survive with ZAR1600 with my kids? There are the things that frustrate me more."* *Participant H. "It extremely affected my relationship because I am here in Cape Town alone and he is in Eastern Cape as I had to move for better treatments and medications in the Western Cape ... we are still having a relationship, but it is no longer the same".*	Marital Uncertainty
Inability to accept a child's disability. Fathers abandon wife and child over disability	Participant E, *"… he told me that he never gave birth to a disabled child ..."* *Participant G "the father of my child left me the first time I told him that the child has a disability."*	Absent Father

Source: Own illustration

4.3.1.1 Unemployment and Caregiving

The failure of the caregiver to seek employment as a result of the pressing need to attend to the child often exert financial burdens upon them. Participants in the study indicated to be primary caregivers by virtue of them being biological mothers of the children with special needs, they automatically have the need to ensure that their child has the best care, and the best care is the care that they themselves give to the child. Although all participants indicated that they received a disability grant to the sum of ZAR1600 it was not enough to fend for the needs of their children.

Participant F, although she showed appreciation on the value of the grant, commented by saying that, "It is really not enough even for the child as they need clothing nappies, special foods and transport when attending doctors' appointments". More needs to be done to assist caregivers in this regard.

4.3.1.2   Marital Uncertainty

It is also interesting to note that even caregivers who have support from their husbands still experience anxiety and fear of being left. Participant D stated that, *"I also think of the future. What if my husband leaves us? How are we going to survive with ZAR1600 with my kids? There are the things that frustrate me more."* There is an inherent fear of being left because there is a direct reliance on the pecuniary contribution made by the father figure in the home as he is the one who is available for employment. Women in these situations are thus economically disempowered because although they have the desire to also work and seek employment and have an income, they unfortunately cannot do so in the circumstances.

This creates the need to question cultural expectations and therefore the roles attached to gender differences in caregiving cannot go unnoticed. According to Ndadzungira (2016) the difference of roles should however not be mistaken to mean that the woman should be only caregiver attending to the child's daily needs. Both the father of the child as well as the mother should establish by consensus, duties and responsibilities on caring for the child. A father's role in being co-caretaker of the child should not be easily unilaterally extinguished by the father who simply chooses to leave without making any coherent contribution to the child's sustenance and daily care.

The issue is further exacerbated because even the caregivers who have partners or are married, they too live in the constant fear that their partners or husbands will one day desert them. There is therefore an extra layer of oppression here because they are forced to rely on the income that the male counterpart brings back home and because they cannot go out and find work themselves, they begin to live in the anxiety that their partner or husband will one day simply leave. Participant G already experienced this, and she noted that, *"the father of my child left me the first time I told him that the child has a disability".* This is disconcerting because it shows that it is the women who become the primary caregivers without any help from the fathers of the children who decide to leave.

Oti-Boadi (2017) asserts that caregivers often find themselves isolated from family and friends due to the demands and course of events that come as a result of taking care of a child with special needs. Thus, the plight of caregivers impacts the emotional wellbeing as they seek to balance between the perceived cause of disability by society, their expected role of caregiving and coping with everyday livelihood challenges to provide for the child.

Participant H was forced to move to Cape Town for better medical care of the child. Her relocation meant that she would be leaving the father of her child behind and she comments on this by saying, *"It extremely affected my relationship because I am here on Cape Town alone and he is in Eastern Cape as I had to move for better treatments and medications in the Western Cape ... we are still having a relationship but it is no longer the same"*.

Female caregivers therefore find themselves in positions where they lose not only social support but also the support of their counterparts. It is unfortunate that the relationship between the mother and father of the child disintegrates in some way because of the amount of time that the former spends in caring for the child. Cramm and Nieboer (2011) assert that there is a need to educate fathers of children with special needs to help them to understand that the responsibility of caretaking is a mutually shared responsibility, one that requires contribution of both parents, not only the mothers. The lack of paternal involvement therefore impacts on both the mother of the child and the child themselves.

4.3.1.3   *Absent Father and the Financial Burden*

Financial challenges of caregivers who find themselves in situations where the father figure is absent, is made worse when the caregivers have no information of alternative recourse (Ambikile & Outwater, 2012). The reasons why a father of a child with special needs may decide to leave are several, it can include the intentional choice to bear the responsibility of caring for a child or maybe the unwarranted view that a child with special needs is a bad omen or the simple rejection of the child because of their disability. Participant G notes that*, "... he told me that he never gave birth to a disabled child ..."*. There is denial by the biological father that the child with special needs is in fact his. Again, this places the mother of the child in a worse economic position because she has to try to make ends meet by herself. According to Baffoe (2013) the influence of traditional belief systems often discourage financial participation of family members as disability is often devalued and looked down upon as a curse or a spiritual curse.

The lack of knowledge of alternative means of enforcing care from the father results in fathers being either absent or taking a part-time role in caregiving for their child. Oti-Boadi (2017) asserts that primary caregivers should be educated about the possibility of seeking legal recourse to ensure they are assisted to foot the costs involved in caring for a child with special needs.

4.3.2 Access to Services

McNally and Mannan (2013) allude that the lack of money for necessities and the lack of money of healthcare often hinder caregivers to access the necessary services. However, in some instances, as noted by Taderera and Hall (2017) the available resources may not be accommodating children with special needs, often in education institutions, transport and other public infrastructures meant to be accessible by everyone. The study's second objective sought to explore the experiences of access to services (healthcare, education, social care). Participants in the study indicated that they had challenges in accessing healthcare and education. The table below summates the inductive findings and emerging themes to this objective.
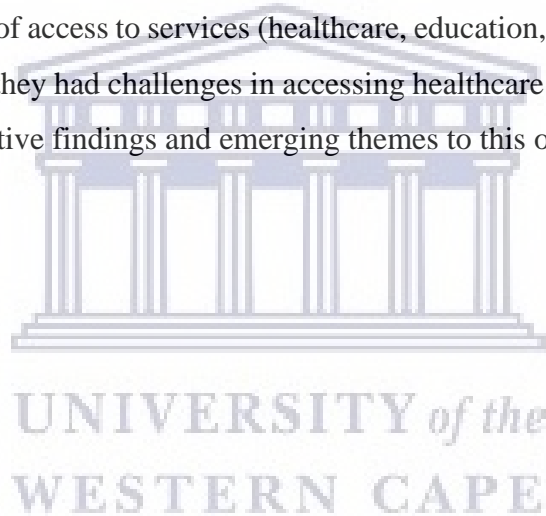
Table 4.3:   Caregivers Access to Services

What are the experiences of caregiver's access to services (healthcare, education, social care)?		
Codes	**Notable Participant Input**	**Emerging Theme**
Inability to access schools with special needs facilities Un-accommodative schooling environment	Participant D *"there are no schools that can accommodate my child for me to look for employment. You are liable to make sure that your child is taken care of and is safe."* Participant C. *"It is difficult to have a disabled child because I cannot get a school and I cannot stay without her and the schools that I tried, they are not treating my child well."* Participant B *"A disabled child is very scared of the cold and sometimes those schools do not know how to keep them warm. The tile is not okay for a disabled child and they need to have a bed so they don't sleep on the floor."* *"I did take her out of the creche because she was not coping."*	Inaccessible Education facilities
Delayed diagnosis of disability	Participant E *"once gave an appointment for physio but she cried a lot and the physiotherapist could not continue with the session and he took my number promising to call me for another appointment but until today I had not received any call."* Participant A *"the income for the household is very small and her disability grant is not enough as I have to hire transport to take us to Tygerberg for appointments."*	Access to Health Care services

Source: Own illustration

4.3.2.1   Education

ILEA (Fish Report) (1985) argues that integration is dependent on external agency in which the agency of the child factors into admission requirements. This view is referred to by participant C, who says that *"I did take her out of creche because she was not coping"*. Her comment shows that a child with special needs may actually struggle to cope within the schooling environment and the reasons for this are myriads. Inclusion therefore brings the focus on the school system to accommodate every child regardless of their disability to ensure that each

child copes or at least learns to do so in a healthy learning environment. This should be done in a way that allows the children to feel as if they actually belong.

Some of the difficulties of taking a child with special needs to a school are clearly outlined by Participant E who states that, *"It is difficult to have a disabled child because I cannot get a school and I cannot stay without her and the schools that I tried are not treating my child well. Sometimes she gets sick because they do not adjust her sitting position"* Participant E highlights the many concerns that a caregiver will have to consider to simply take their child to school. As she has outlined, these include, the building structure, whether it is warm enough to accommodate the child in a way that ensures that they are warm and secure; the readjustment of the child's sitting position and the need to always check up on the child in instances where the child cannot communicate. All of these requirements require that there be a child-minder who in some cases should be specialized caring for a child with a disability.

Participant E further suggests that schools that cater for children with special needs should separate the children in accordance with their disability. She states that, *"In a school for children with autism they should separate the] because the child with autism is dangerous to my child because mine cannot even move an arm.* Her concern highlights that schools should look at the specific disability and evaluate the type of learning environment that is best suited for the child. Safety is important, and children will at times want to play and interact however even the most innocent of interaction amongst children can have detrimental consequences for a child with a different type of special need. Ndadzungira (2016) asserts that the capacity to adapt to various learning environments is therefore limited as some children with special needs are more sensitive in comparison to others.

Inclusive education is thus about responding to diversity and even within the schools specially designed for children with special needs, there may still be a need to realize such diversity. Moreover, this issue also overlaps with that of financial costs above in that the caregivers may fail to pay or afford the extra costs that come with taking the child to school (Oti-Boadi, 2017; Cramm & Ouweti, 2013). They are thus limited to seeking admission at the schools surrounding them. Participant F notes that, *"you cannot move … there are no schools that can accommodate my child for me to look for employment".* Since children with special needs are a minority, the schools at which they may seek admission may find no incentive in including them.

This can be seen in what Participant A points out when she says, "… she cannot find school. I am still on the waiting list at Noluthando, I do not know when they will call to confirm that she got a place or not. This is the most challenging thing for me because other children do go to school and she cannot". Participant G further reiterated this point by saying that, "I also want her to go to school but I hardly can get a school. The schools here in Khayelitsha are not accommodating Mfuleni children because there is no transport to Mfuleni". The difficulty in finding schools that are inclusive of children with special needs especially in the areas in which the participants reside has thus been proven to be difficult.

4.3.2.2 Healthcare

The use of language and the manner in which such information is communicated becomes the setting stone of how the biological parents and/or caregivers accept or reject the disability of their child. Medical practitioners therefore have an ethical duty to be able to communicate sensitive information in a manner that fosters acceptance and clarity. The impact of language as a barrier to efficient health care cannot go unnoticed. This is especially true within the South African context where the English language can itself function as a language barrier amongst indigenous people. When doctors or health practitioners communicate the disability to the parents or caregivers in English for example, this can already become a deterrent to understanding the condition of the child as well as enforcing acceptance. Hedov, Wikblad and Annere (2002) argue that *'thoughtlessness by professionals, or ill-informed comments, however trivial, may have deep and long-lasting effects on the fragile beginning of a new balance for the family'*. The behaviour of professionals and the lack of information is referred to by the participants as one of the reasons why it was challenging to accept the disability of their children and their difficulty to cope as illustrated in the following quotation by participant E, "*...he [physiotherapist] took my number promising to call me for another appointment but until today I had not received any call*" .

4.3.3   Perceptions towards Children with special needs

Perception on children with special needs has often been influenced by social systems, belief systems and exposure to the body of knowledge on disability. Noting the work of Cherchas (2014), Oti-Boadi (2017), McNally and Mannan (2013) they allude at most caregivers are often isolated as result of the association of disability with belief systems, the supposed infidelity of the mother and the lack of knowledge of disability. The study's third (3rd) objective sought to

explore the caregiver's perceptions of family, service providers and community member's reactions towards their children with special needs. Participants noted how family members (husband, in-laws, sisters) were not willing to accept them and gave names to their children. The participant notes the scathing derogatory names that are branded on their children with communities and how its emotional upsets them. The table below summates the notable participant input from the findings and the emerging themes.

Table 4.4:   Perception towards Children with Special Needs

What are the perceptions of family, service providers and community member's reactions towards their children with special needs?		
Codes	**Notable Participant Input**	**Emerging Themes**
Lack of knowledge on disability creates stereotypes in families	*"Even now his mother does not even bother supporting him (husband) with this child though she is staying here in Cape Town."* *"They will call your child with names like cripple (isidalwa) and people commenting they do not have a cripple in their family."* *"I told my family, but they were in denial telling me that my child is okay."*	Disability & Denialism in Family
Infidelity a cause for disability	*"They were influencing him not to meet his child … [they also said] that I had another man that I was sleeping with because their brother and family cannot have disabled children."*	Disability Stereotypes in Communities

Source: Own illustration

4.3.3.1   Family and Caregiving

Participant E, "At first his family did not want him to involve himself with his child as they said that in their family there are no disabled children. They were influencing him not to meet his child … [they also said] that I had another man that I was sleeping with because their brother and family cannot have disabled children". According to Oti-Boadi, (2017), The perceptions of children with special needs within the African context can be problematic. In this case the disability of the child led to accusations of promiscuity against the participant and blaming her for the child's condition. This is unfortunate because it shows that the biological mothers of

children with special needs can be subjected to stigma and may be rejected because of the child's condition.

Parents who receive social support are most likely to relate better emotionally to their children and engage more positively in interactions with them. According to Ndadzungira (2016) family support is important because it helps the caregiver to be able to accept their child and find effective resolutions of caring for the child. The lack of family support can cause the caregiver to reject the child and blame themselves or question what they did to deserve a child with special needs. This was seen in Participants G reflection in which she stated that, *"I could not even look at my child that time. I asked myself what I did to do deserve this".* There is often some self-blame that emanates from caregivers as they think that it is their fault that the child has special needs. Questions such as one posed by participant G above shows that the immediate reaction to having a child with special needs is seeing it as a curse or form of punishment.

Participant F also noted that, "It took time for my family to accept that I have a disabled child. My siblings would pass comments like, 'when are you going to put your cripple down' yet they could see there are only four chairs which are all occupied, so where would they want me to put my child? My husband and my kids are very supportive". This comment shows that it is often hard for a family to support a caregiver with a child with special needs. The language used by family members when communicating with the caregiver about their child also shows that there is also stigma that emanates from the family itself.

4.3.3.2   Disability stereotypes in Communities

Furthermore, the community itself may tend to stigmatize against children with special needs. The stigma can be directly linked to the failure to understand the disability. Participant E stated that, *"they will call your child names like cripple (isidalwa) and people will comment that they do not have a cripple I their family".* Inclusivity of children with special needs therefore needs to be established within the community in order for it to be enforced into schools. The community itself should refrain from stigmatizing children with disabilities and should rather seek to understand the nature of the disability and offer communitarian help. This will not only be in line with the embodied constitutional values of ubuntu but it will further create an environment where the caregiver and the child with special needs does not feel neglected and isolated.

Participant F, *"sometimes people will ask why the child does not walk and will pass remarks when I carry her on my back saying she is too old why can't she walk? Do they think that you can just carry a big heavy child on your back for no reason?"*. The insensitive comments by members of the community are insensitive to both the child and the caregiver. The stigma, name calling, and stares can all contribute to the disintegration of the caregivers' state of mind and the caregiver may therefore find themselves suffering from depression amongst other mental illnesses as a result. Goffman (1963) argues that stigma not only affects the experiences of those with the stigmatizing characteristic but that it also affects those with whom that individual is associated with. Caregivers thus contract what is called courtesy stigma as a result of their positionality as parents and primary caretakers of the children with special needs.

4.3.4 Coping Strategies applied by Caregivers

The plight of caregivers, their stress, feelings of isolation, and financial challenges are emphasized in various studies (Gona et al., 2010; Taderera & Hall, 2017). Traditional beliefs have been at the center of blame for breeding stereotypes and stigma on children with disabilities, yet in some instances in some communities' hope, social support and counselling have emanated. While participants in the study indicated their feelings of isolation, their pain in face of the community's perceptions they gave reference to church, counselling and social support structures as pillars to them coping with the caregiving.

Table 4.5:   Coping Strategies applied by Caregivers

What are the coping strategies implemented by families with children with special needs?		
Codes	**Notable Participant Input**	**Emerging Themes**
Support Group	*"I wrote to the support group that I do not have food for my child and those who were closer came to me with food for me and my child …"*. *"I only attended once but it made a difference as I heard people sharing the same problems and some that were even worse and that made me look at my situation differently"*.	Support Groups

Source: Own illustration

4.3.4.1   Support Groups

Almost all the participants indicated that they attend a support group at least once a week. The support group functions as an alternative to family support, it is helpful especially in instances where the family is not being supportive, and the caregivers stand in the gap for each other. The impact of a support group can therefore not be underrated because it positively influences the caregivers in that they are motivated to do more for their children (Taderera & Hall, 2017). The support group constitutes caregivers who all have children with special needs and because they all know the challenges that they face, they are able to encourage one another and give support to each other.

Participant C gives an example when she says that, *"I wrote to the support group that I do not have food for my child and those who were closer came to me with food for me and my child …"*.

The support group also functions as a source of comfort as was indicated by Participant H, "*I only attended once but it made a difference as I heard people sharing the same problems and some that were even worse and that made me look at my situation differently*". Through the support group, the caregivers are able to realize that having a child with special needs, although it is challenging, is in itself not a death sentence (Bringham, 2017). It is therefore a good coping mechanism and a cost-effective alternative to therapy or counselling for the caregivers.

4.4   STUDY LIMITATIONS

The lack of fathers being recruited for the study is a limitation. Fathers could have provided a different perception and experience to that of mothers. The fact that all the mothers were recruited from one organisation is also a limitation as the children had similar conditions. A sample from a broader population could have expanded the findings of the study. Applying a qualitative methodology means that although the study design can be replicated the findings is only limited to the specific research setting.

4.5   CHAPTER SUMMARY

This chapter has discussed the challenges that caregivers face in caring for children with special needs. It has outlined the four themes that emanated from the research. The paper has shown that more needs to be done to offer support to caregivers as they often face difficult ordeals in trying to meet the needs of the child. The responsibility of caregiving is often taken up by mothers of the child with special needs and she often experiences more difficulty because she also cannot find work but has to always ensure that optimum care is given. The responsibility of caregiving is thus more stringent on mothers than it is on fathers of the child. The themes that were identified can be conceptualised within the conceptual framework the ICF specifically the participation and environmental factors. The mothers expressed the influences of attitudinal barriers and how these affected their children with specific reference to cultural stereotypes.

CHAPTER FIVE
SUMMARY AND CONCLUSION

5.1   INTRODUCTION

The research explored the perceptions and experiences of caregivers of children with special needs around Cape Town surrounding areas. Using semi-structured interviews, a qualitative research tool, eight participants were drawn from Mfuleni using purposive sampling. The research sought ethical clearance from the University, to which participant letter of consent was signed by the researcher and participant before or after the semi-structured interview. The participant's consent was discussed through the entire interview process and thereafter.

This chapter will provide a summary of the research study, provide for recommendations, and provide the research study conclusion. The summary will present the research study findings. Drawing from the findings and discussion in chapter four, the chapter will provide for recommendations. The latter part of this chapter will provide the conclusion.

5.2   SUMMARY OF FINDINGS

5.2.1   Objective 1: Caregivers Experiences

In exploring the experiences of caregivers with children with disabilities, participants explained that due to the demand in caregiving, they could not look for other forms of employment and spent the entirety of their time with the child. As a result of unemployment these mothers lacked the financial muscle to fend for themselves and foot the expenses needed to take care of their children. Participants who were all females indicated that their family and father of the children were not supportive in taking care of the child.

5.2.2   Objective 2: Access to services

Although there was consensus among the participants in the study to seek education and healthcare services for their children. Due to the cost of health care the grant money was not enough to supplement the extra resources needed in the welfare of the child. Participants noted that schools were not accommodating enough of their children's needs and in as much as they

wanted them to be educated, they expressed their fears and uncertainty in the treatment of their children.

5.2.3 Objective 3: Perceptions towards children with special needs

Stigmatisation, discrimination and isolation are a continued experience in the lives of caregivers as family and community are often in denial and are persuaded by their traditional beliefs to shun children with special needs and their cares. For some the causes of disability went as far as suspecting infidelity of the woman as scapegoat to disassociate with the disabled child.

5.2.4 Objective 4: Caregivers coping strategies

Participants in the study indicated that they were in support groups and for some they attained counselling. Support groups presented them as means to cope with the needs of their children. In identifying themselves together with others in support group participants found strength to attend to their children with love and care regardless of the many stereotypes.

5.3 RECOMMENDATIONS

The study recommends the following:

a) Government and related institutions provide education on the various forms of disability and educate them on the symptoms so that they can seek medical help early.

b) Educators to attain more training and skills capacitation on how to include children with special needs in school settings.

c) There is a need for informed budgetary allocation on the part of the government in providing for children with special needs.

d) There is a need for research in understanding the plight of caregivers in dealing with disabled children with special needs.

5.4 CONCLUSION

In seeking to unpack the experiences, perceptions and challenges faced by caregivers in attending to children with special needs. The study employed qualitative research methods with participant's selection done through Uhambo and non-profit organization. Participants in the study were purposively selected to meet the research aims and objectives. Literature drawn in

the study held that although the experiences of the caregivers varied due to their economic or financial status, the majority of the caregivers lacked institutional support. Despite the credible and relevant policy frameworks revised by the government, there remained a paucity in the interpretation of these policies and their implementation, the literature attested. Literature drawn showed that discrimination and stereotypes anchored on religion, culture and lack of information were perpetual within South Africa and beyond.

The findings cemented the notion that fathers were less proactive in supporting children with special needs. The study findings noted that although communal education on children with special needs was being done, stereotypes and discrimination of children with special needs was perpetual. Although the literature had shown profound psychological challenges that often-affected caregivers in coping with children with special needs. The findings illuminated efforts done to provide counselling and help to caregivers though it was still marginal. The recommendations of the study highlight the need for government elaborate intervention on the welfare and education of children with special needs.

REFERENCE LIST

ACPF (2011). *Children with disabilities in South Africa: The hidden reality*. Addis Ababa: The African Child Policy Forum.

Alpaslan, A.H. (2010). *Social work research: Only study guide for SCK4810*. Revised edition. Pretoria: University of South Africa.

Australian Bureau Statistics (2016). Census of Population and Housing: Census Dictionary.

Babbie, E.R. (2012). *The practice of social research* (13th edition). United States of America: Cengage Learning.

Babbie, E., Mouton, J., Vorster, P. & Prozesky, B. (2007). *The practice of social research* (7th edition). South Africa: Oxford University Press Ltd.

Baffoe, M. (2013). Stigma, discrimination, and marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, 3(1):187-198.

Baker, B.L., Blacher, J. & Olsson, M.B. (2005). Preschool children with and without developmental delay: Behavioural problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 49:570-590.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9):702-714.

Boadi, M. (2017). Exploring the lived experiences of mothers of children with intellectual disability in Ghana. *SAGE Open,* 7(4).

Bodde, A.E. (2009). A review of social and environmental barriers to physical activities for children with intellectual disability. *Journal of Disability and Health*, 2(2):57-66.

Cauda-Laufer, A.N. (2017). Raising a child with a disability: Coping mechanisms and support needs. Unpublished Degree of Doctor of Psychology. Philadelphia: Philadelphia College of Osteopathic Medicine Department of Psychology.

Census (2011). Profile of persons with disabilities in South Africa / Statistics South Africa. Pretoria: Statistics South Africa, 2014 Report 03-01-59 210 pp ISBN 978-0-621-42793-6

Coetzee, O. (2015). Caregiving experiences of South African mothers of adults with intellectual disability who display aggression: Clinical case studies. Unpublished Doctoral Dissertation. Cape Town: University of Cape Town.

Cooper, S.-A., Smiley, E., Jackson, A., Finlayson, J., Allen, L., Mantry, D. & Morrison, J. (2009). Adults with intellectual disabilities: Prevalence, incidence and remission of aggressive behavior and related factors. *Journal of Intellectual Disability Research*, 53(3):217-232.

Cramm, J.M. & Nieboer, A.P. (2011). Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities*, 15(2):101-113.

Creswell, J.W. (2009). *Research design, qualitative, quantitative and mixed methods approaches* (3rd edition). Thousand Oaks, CA: Sage Publications.

Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd edition). London: Sage Publications.

De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. (2002). *Research at grass roots for the social sciences and human professions* (2nd edition). Pretoria. Van Schaik Publishers.

De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. (2005). *Research at grass roots: For the social sciences and human professions* (3rd edition). Pretoria. Van Schaik Publishers.

De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. (2011). *Research at grassroots for social science and human professions*. Pretoria: Van Schaik Publishers.

Department of Social Development (2008). Annual Report. Available at: https://www.gov.za/documents/department-social-development-annual-report-20082009

Disabled World Report. (2011). retrieved from: www.disabledworld.com/disability/types

Du Plessis, M.C. (2015). Access to work for disabled persons in South Africa: the intersections of social understandings of disability, substantive equality and access to social security. Unpublished thesis, Doctor of Philosophy. Cape Town: University of Cape Town.

Edmonds, L.J. (2005). Disabled People and Development. Poverty and Social development Papers No. 12. Asian Development Bank.

Inner London Education Authority (1985). Equal opportunities for all? (The Fish report). London: ILEA.

Fossey, E., Harvey, C., Mokhtari, M. & Meadows, G. (2012). Self-rated assessment of needs for mental health care: A qualitative analysis. *Community Mental Health Journal*, 48(4):407-419.

Geiger, M. (2012). Communication training for centre based carers of children with profound disabilities in the Western Cape. *African Journal of Disability*, 1(1):1-8.

Gibbs, G.R. (2007). *Analysing qualitative data*. London: SAGE Publications.

Quinn, N. & Evans, T. (2010). Understanding the carers' experience? Examples from a Ghanaian context. *International Social Work*, 1(53):61-72.

Gona, K. Mung'ala-Odera, V. Newton, C.R. & Hartley, S. (2010). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child Care Health Development*, 37(2):175-183.

Goodley, D. (2011). *Disability studies. An interdisciplinary introduction*. Los Angeles: SAGE Publications.

Goodley, D. & Lawthorn, R. (2006). *Disability and psychology: Critical introductions and reflections*. Hampshire: Palgrave Macmillan.

Graham, L., Moodley, J. & Selipsky, L. (2013). The disability-poverty nexus and the case for a capabilities approach: Evidence from Johannesburg, South Africa. *Disability & Society*, 28(3):324-337.

Green, S.E. (2003). "What do you mean 'what's wrong with her?'" stigma and the lives of families of children with disabilities. *Social Science & Medicine*, 57(8):1361-1374.

GSDRC. (2015). Governance, Social Development, Conflict Resource Centre. Available from: https://gsdrc.org

Hassall, R. & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy*, 33(1):71-88.

Hashe, A. (2020) Strategies of parents to ensure the health and well-being of their children with disabilities: A human capabilities approach. Unpublished Master Thesis. University of the Western Cape.

Heller, T., Hsieh, K. & Rowitz, L. (1997). Maternal and paternal caregiving of persons with mental retardation across lifespan. *Family Relations: An Interdisciplinary Journal of Applied Family Studies,* 46(4):407-415.

Heidegger, M. (1927/1962). *Being and time* (Trans. J. Macquarrie & E. Robinson). Oxford: Blackwell.

Husserl, E. (1900/1970). *Logical investigations* (Trans. J.N. Findlay). New York: Humanities Press.

Husserl, E. (1936/1970). *The crisis of European sciences and transcendental phenomenology* (Trans. D. Carr). Evanston: Northwestern University Press.

Jack, J.-L. (2016). Parent experiences and coping processes when raising children with Asperger syndrome: Challenges, turning points and building resilience. Unpublished thesis for the degree of Doctor of Philosophy. Wellington, New Zealand: Victoria University of Wellington.

Kadungure, P.T. (2017). Experiences of Caregivers caring for children with different special needs in a cluster foster care village in KZN. Unpublished thesis for Master of Social Work. Durban: University of KwaZulu-Natal, Howard College.

Kermanshahi, S.M., Vanaki, Z., Ahmadi, F., Kazemnejad, A. & Azadfalah, P. (2008). Children with learning disabilities: A phenomenological study of the lived experiences of Iranian mothers. *International Journal of Qualitative Studies on Health and Well-being*, 3(1):18-26.

Kittay, E.F., Jennings, B. & Wasunna, A.A. (2005). Dependency, difference and the global ethic of long-term care. *The Journal of Political Philosophy*, 13(4):443-469.

Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E. & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2):89-95.

Kvale, S. (1996). *Interview views: An introduction to qualitative research interviewing*. Thousand Oaks, CA: SAGE Publications.

Langdridge, D. (2007). *Phenomenological psychology. Theory, research and method*. Harlow UK: Pearson Education Limited.

Langdridge, D. (2008). Phenomenology and critical social psychology: directions and debates in theory and research. *Social and Personality Psychology Compass*, 2(3):1126-1142.

Larkin, M., Eatough, V. & Osborn, M. (2011). Interpretative phenomenological analysis and embodied, active, situated cognition. *Theory & Psychology*, 21(3):318-337.

Mabusela, M.D. (2010). An investigation of the challenges and coping mechanisms of homebased caregivers for patients living with HIV in Mamelodi. Unpublished Master's thesis. Pretoria: University of South Africa.

MacLachlan, M. & Mannan, H. (2014). The World Report on Disability and its implications for rehabilitation psychology. *Rehabilitation Psychology*, 59(2):117-124.

MacLachlan, M. & Swartz, L. (2009). *Disability and international development: Towards inclusive global health*. New York: Springer.

McNally, A. & Mannan, H. (2013). Perceptions of caring for children with disabilities: Experiences from Moshi, Tanzania. *African Journal of Disability*, 2(1):1-10.

Maree, K. (2007). *First steps in research*. Pretoria: Van Schaik Publishers.

Marlow, C. (2007). *Research methods for generalist social work*. Belmont: Cengage Learning.

Marlow, C. (1998). *Research methods for generalist social work*. Grove, USA: Brooks/Cole.

Marshall, C.R. & Rossman, G.B. (1997). *Designing Qualitative Research*. London: SAGE Publications.

MDRC. (2016). Michigan Disability Rights Coalition. Available from: https://www.causeiq.com/organizations/michigan-disability-rights-coalition,382435517/

Barnes, C. & Mercer, G. (Eds.) (2004). *Implementing the social model of disability: Theory and research* (pp. 12-23). Leeds, England: Disability Press.

Mhaule, V.N. & Ntswane-Lebang, M.A. (2009). Experiences of caregivers of individuals suffering from schizophrenia in rural areas of the Mpumalanga Province of South Africa. *African Journal of Nursing and Midwifery*, 11(1):118-136.

Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies*, 16(4):236-247.

Muderedzi, J. (2006). Coping behaviours of families of preschool children with disabilities; A cultural perspective from Zimbabwe. Unpublished Master Thesis. Oslo: University of Oslo.

Muderedzi, J.T., Eide, A.H., Braathen, S.H. & Stray-Pedersen, B. (2017). Exploring structural violence in the context of disability and poverty in Zimbabwe. *African Journal of Disability*, 18(6):274.

Muthukrishna, N. & Ebrahim, H. (2014). Motherhood and the disabled child in contexts of early education and care. *Childhood*, 21(3):369-384.

Ndadzungira, A. (2016). The experiences of primary caregivers caring for children with physical disabilities in Hardap region of Namibia. Unpublished thesis for the degree Masters of Arts in Social Work. Johannesburg: University of the Witwatersrand.

Neuman, W.L. (2011). *Social research methods: Qualitative and quantitative approaches* (7th edition). Boston, MA: Allyn & Bacon.

Opperman, S. & Alant, E. (2003). The coping responses of the adolescent siblings of children with severe disabilities. *Disability and Rehabilitation*, 25(9):441-454.

Oxford Advanced Learner's Dictionary. (2010). Cape Town: Oxford University Press.

Ross, E. & Deverell, A. (2010). *Health, illness and disability: Psychosocial approaches* (2nd edition). Pretoria: Van Schaik Publishers.

Polit, D. F., & Beck, C. T. (2014). *Essentials of nursing research: appraising evidence for nursing practice.* 8th ed. Philadelphia: Wolters Kluwer Health /Lippincott Williams & Wilkins.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information Journal*, 22(1):61-75.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11(2):261-71.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis. Theory, method and research*. London: SAGE Publications.

Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology* (pp. 53-80). London, England: SAGE Publications.

Streubert-Speziale, H.J. & Carpenter, D.R. (2003). *Qualitative research in nursing: Advancing the humanistic imperative* (3rd edition). Philadelphia: Lippincott Williams and Wilkins.

Taderera, C. & Hall, H. (2017). Challenges faced by parents of children with learning disabilities in Opuwo, Namibia. *African Journal of Disability* 6:283. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5566178/

Tancred, E.-M. & Greeff, A.P. (2015). Mothers' parenting styles and the association with family coping strategies and family adaptation in families of children with ADHD. *Clinical Social Work Journal*, 43(4):442-451.

Taylor, J.L., Novaco, R. W., Gilmer, B. & Thorne, I. (2002). Cognitive-behavioural treatment of anger intensity among offenders with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(2):151-165.

Terre Blanche, M., Durrheim, K. & Painter D. (2006). *Research in practice: Applied methods for social science*. Cape Town: UCT Press.

Terre Blanche, M. & Durrheim, K. (2011). Histories of the present: Social science research in context. In: M. Terre Blanche, K. Durrheim & D. Painter (Eds.), *Research in practice* (pp. 1-17). Cape Town: University of Cape Town Press.

Thoya, M. J (2017) Experiences of parents regarding rehabilitation of their children with Cerebral Palsy in Khayelitsha Cape Town. Unpublished Master Thesis. University of the Western Cape.

Thsitake, R.S., Pengpid, S. & Peltzer, K. (2013). Knowledge and experiences of childcare workers regarding care and management of children with special needs in Gauteng, South Africa. *Journal of Child & Adolescent Mental Health*, 25(2):131-138.

Tregaskis, C. (2004). Social model theories and non-disabled people: Some possibilities for connection. In: C. Barnes & G. Mercer (Eds.) *Implementing the social model of disability: Theory and research* (pp. 65-82). Leeds: The Disability Press.

UNCRPD (2006). United Nations Convention on the Rights of Persons with Disabilities

UNDP (2013). Human Development Reports.

Utsey, S.O., Adams, E.P. & Bolden, M. (2000). Development and initial validation of the Ag ricultural Coping Systems Inventory. *Journal of Black Psychology*, 26:194-215.

Vanegas, S. B and   Abdulrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. Journal of Family Social Work. Routledge. 19 (4), 286-327

Vergunst, R. (2016). Access to Health Care for Persons with disabilities in rural Madwaleni, Eastern Cape South Africa.

World Health Organisation. (2001). Fifty Fourth World Health Assembly. Available at: https://apps.who.int/iris/handle/10665/260183

World Health Organisation. (2011). World report on disability. Available at: https://www.who.int/teams/noncommunicable-diseases/disability-and-rehabilitation/world-report-on-disability

ETHICAL CLEARANCE APPLICATION FORM

UNIVERSITY OF THE WESTERN CAPE

(HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE)

PLEASE NOTE THAT THE FORM MUST BE COMPLETED IN TYPED SCRIPT. HANDWRITTEN APPLICATIONS WILL NOT BE CONSIDERED

SECTION 1: PERSONAL DETAILS

1.1	Surname of Applicant:	Matambanadzo
1.2	First names of applicant:	Priscilla Amanda
1.3	Title (Ms/ Mr/ Mrs/ Dr/ Professor Etc.):	Ms
1.4	Applicant's gender:	Female
1.5	Applicant's Race (African/Coloured/Indian/White/Other):	Black
1.6	Student Number (where applicable):	3614048
	Staff Number (where applicable):	
1.7	School:	Child and family Studies
1.8	College:	University of the Western Cape
1.9	Campus:	
1.10	Existing Qualifications:	Bachelor of Social work (2015)
1.11	Proposed Qualification for Project:	MA. Child and family studies (In the case of research for degree purposes)

2. CONTACT DETAILS

Tel. No.	021- 5102998
Cell. No.	0794632507
E-mail	priscillamatambanadzo@yahoo.com
Postal address (in the case of students and external applicants)	11 Dagbreek Court 44 Spencer Street Maitland 7401

3. SUPERVISOR/ PROJECT LEADER DETAILS

NAME	TEL. NO.	EMAIL	SCHOOL / INSTITUTION	QUALIFICATIONS
Anthea Rhoda	082 7757748	arhoda@uwc.ac.za	University of the Western Cape • Stellenbosch University • Stellenbosch University • University of the Western Cape	PhD Physiotherapy (2010) MSc Medical Sciences (Rehabilitation) (2002) • Bachelor of Social Work (Honours) • Physiotherapy (1996) BSc Physiotherapy (1988)

SECTION 2: PROJECT DESCRIPTION

Please do *not* provide your full research proposal here: what is required is a short project description of not more than two pages that gives, under the following headings, a brief overview spelling out the background to the study, the key questions to be addressed, the participants (or subjects) and research site, including a full description of the sample, and the research approach/ methods

2.1 Project title

Perceptions, experiences and coping strategies of families caring for children with special needs.

2.2 Location of the study (where will the study be conducted)

Western Cape, South Africa. Specifically, Khayelitsha, Mfuleni, Athlone and Mitchells Plain

2.3 Objectives of and need for the study

To explore the experiences the (physical, social, psychological, emotional, financial) of families caring for a child with special needs.

Explore and assess the family life of families with special needs children and their coping strategies.

To explore the experiences of access to services (healthcare, education, social care)

To explore the families' perceptions of family and community member's reactions towards their children with special needs.

The research findings can assist relevant departments (Health, social services, education), with planning and implementing programmes to support families of children with special needs. Most of the previous research done focused on the experiences and coping strategies for mothers and left out other carers who may not necessarily be mothers. This study will also look at the carer's perceptions on the effects of disability on the whole family.

2.4 Questions to be answered in the research

(Set out the critical questions which you intend to answer by undertaking this research.)

What are the perceptions, challenges and coping strategies of families caring for a child with special needs?

2.5 Research approach/ methods

(This section should explain how you will go about answering the critical questions which you have identified under 2.4 above. Set out the approach within which you will work, and indicate in step-by step point form the methods you will use in this research in order to answer the critical questions – including sample description, sampling strategies, data collection methods, and data reduction strategies.

- A descriptive exploratory, qualitative research design will be used in this study.
- Participants will be recruited into the study from areas around cape town
- The population will consist of people caring for children with special needs children
- Purposive sampling will be used for this project.
- In depth interviews will be conducted by the researcher for the stroke patients.
- Data will be analyzed using the six steps of thematic analysis by Braun & Clark, 2006.

For a study that involves surveys, please append a provisional copy of the questionnaire to be used. The questionnaire should show how informed consent is to be achieved, as well as indicate to respondents that they may withdraw their participation at any time, should they so wish.

2.6 Proposed work plan

Set out your intended plan of work for the research, indicating important target dates necessary to meet your proposed deadline.

STEPS	DATES
Ethical Clearance and permission from facilities	May 2016 – July 2016
Data collection	August 2016 – October 2016
Data Analysis	November 2016 – January 2017
Write up of findings and discussion	February 2017 – May 2017
Submit	June 2017

SECTION 3: ETHICAL ISSUES

The UWC Research Ethics Policy applies to all members of staff, graduate and undergraduate students who are involved in research on or off the campuses of University of the Western Cape. In addition, any person not affiliated with UWC who wishes to conduct research with UWC students and / or staff is bound by the same ethics framework. Each member of the University community is responsible for implementing this Policy in relation to scholarly work with which she or he is associated and to avoid any activity which might be considered to be in violation of this Policy.

All students and members of staff must familiarize themselves with, AND sign an undertaking to comply with, the University's "Code of Conduct for Research".

QUESTION 3.1

Does your study cover research involving:	YES	NO
Children		x
Persons who are intellectually or mentally impaired		x
Persons who have experienced traumatic or stressful life circumstances	x	
Persons who are HIV positive		x
Persons highly dependent on medical care	x	
Persons in dependent or unequal relationships	x	
Persons in captivity		x
Persons living in particularly vulnerable life circumstances	x	
If "Yes", indicate what measures you will take to protect the autonomy of		

THE PARTICIPANTS WILL BE PROVIDED WITH THE NECESSARY SUPPORT AN COUNSELING IF ANY OF THE ABOVE RESPONDENTS AND (WHERE INDICATED) TO PREVENT SOCIAL STIGMATIZATION AND/OR

Should occur. Secondary victimization of respondents. If you are unsure about any of these concepts, please consult your supervisor/ project leader.

QUESTION 3.2

Will data collection involve any of the following:	YES	NO
Access to confidential information without prior consent of participants		x
Participants being required to commit an act which might diminish self-respect or		x
cause them to experience shame, embarrassment, or regret		x
Participants being exposed to questions which may be experienced as stressful or upsetting, or to procedures which may have unpleasant or harmful side effects	x	
The use of stimuli, tasks or procedures which may be experienced as stressful, noxious, or unpleasant		x
Any form of deception		x
If "Yes", explain and justify. If appropriate, indicate what steps will be taken to minimize any potential stress/harm.		

The participants will be provided with the necessary support   counselling if any of the above should occur.

QUESTION 3.3

Will any of the following instruments be used for purposes of data collection:	YES	NO
Questionnaire		x
Survey schedule		x
Interview schedule	x	
Psychometric test		x
Other/ equivalent assessment instrument		x

If "Yes", attach copy of research instrument. If data collection involves the use of **a** psychometric test or equivalent assessment instrument, you are required to **provide** evidence here that the measure is likely to provide a valid, reliable, and **unbiased** estimate of the construct being measured. If data collection involves **interviews** and/or focus groups, please provide a list of the topics to be covered/ **kinds** of questions to be asked.

QUESTION 3.4

Will the autonomy of participants be protected through the use of an informed consent form, which specifies (in language that respondents will understand):	YES	NO
The nature and purpose/s of the research	x	
The identity and institutional association of the researcher and supervisor/project leader and their contact details	x	
The fact that participation is voluntary	x	
That responses will be treated in a confidential manner	x	
Any limits on confidentiality which may apply	x	
That anonymity will be ensured where appropriate (e.g. coded/ disguised names of	x	
participants/ respondents/ institutions)		
The fact that participants are free to withdraw from the research at any time without any negative or undesirable consequences to themselves	x	
The nature and limits of any benefits participants may receive as a result of their participation in the research	x	
Is a copy of the informed consent form attached?	x	
If NO to any of the above: (a) please justify/explain, and (b) indicate what measures will be adopted to ensure that the respondents fully understand the nature of the research and the consent that they are giving.		

QUESTION 3.5

> **Specify what efforts been made or will be made to obtain informed permission for the research from appropriate authorities and gate-keepers (including caretakers or legal guardians in the case of minor children)?**
>
> An information sheet outlining the study will be given to all participants. Once all questions have been answered, they will be asked to sign a consent form.

QUESTION 3.6

> **STORAGE AND DISPOSAL OF RESEARCH DATA:**
> **Please note that the research data should be kept for a minimum period of at least five years in a secure location by arrangement with your supervisor.**
>
> **How will the research data be secured and stored? When and how (if at all) will data be disposed of?**
> The data will be stored in a locked cupboard and electronic files will be stored password encrypted. After 5 years all hard copies will be shredded, using a paper shredder. All electronic data will be deleted.

QUESTION 3.7

> **In the subsequent dissemination of your research findings – in the form of the finished thesis, oral presentations, publication etc. – how will anonymity/ confidentiality are protected?**
> The data will be stored in a locked cupboard and electronic files will be stored password encrypted. After 5 years all hard copies will be shredded, using a paper shredder. All electronic data will be deleted.
> All data will not contain the participants personal information it will be coded.

QUESTION 3.8

Is this research supported by funding that is likely to inform or impact in any way on the design, outcome and dissemination of the research?	YES	NO x
If yes, this needs to be explained and justified.		
If yes, please indicate what the conditions are.		

QUESTION 3.10

Do you or any individual associated with or responsible for the design of the research, have any personal, economic, or financial interests (or) any other potential conflict of interests that **could** reasonably be regarded as relevant to this research project?	YES	NO
	Yes	
If you answered YES to Question 3.10 please provide full details: The researcher is a social worker and used to work with the prospective participants.		

SECTION 4: FORMALISATION OF THE APPLICATION

APPLICANT

I have familiarized myself with the University's Code of Conduct for Research and undertake to comply with it. The information supplied above is correct to the best of my knowledge.
NB: PLEASE ENSURE THAT THE ATTACHED CHECK SHEET IS COMPLETED
DATE: …………………………… **SIGNATURE OF APPLICANT:** ………………………………..

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 2988/2948
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E: research-ethics@uwc.ac.za
www.uwc.ac.za

01 November 2016

Ms P Matambanadzo
Social Work
Faculty of CHS

Ethics Reference Number: HS/16/7/11

Project Title: Perceptions, experiences and coping strategies of families caring for children with special needs.

Approval Period: 30 September 2016 – 31 September 2017

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

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

PROVISIONAL REC NUMBER - 130416-049

FROM HOPE TO ACTION THROUGH KNOWLEDGE

UHAMBO

Research: Parent Baseline Survey

To whom it may concern:

We are happy to assist you with your research and to give further inputs to 12 parents from our support groups. Our edits to the questionnaire has been submitted to you.

Upon agreeing to this partnership, you undertake to:

- Be introduced by Uhambo upon first contact to all parents.
- To inform Uhambo Foundation of your plans as to which parents will be interviewed and when.
- Parents signing a consent form.
- Be sensitive to the context of the parents and the ethics of our work.
- Cover at least 80% of the questions as suggested by Uhambo Foundation with each parent interviewed.
- Report any concerns related to vulnerable children and their families to Uhambo Foundation.
- Submit findings and recommendations prior to submission for final permission particularly with regards to client anonymity.
- Submit final document and findings.
- Reference Uhambo Foundation in relation to any, and all, publications to follow this thesis based on the research undertaken.

In return, Uhambo Foundation commits to:

- Introduce the researcher to appropriate parents of children with disabilities crossing a variety of socio-economic factors.
- Ensure a welcoming environment for the researcher.
- Provide guidance in relation to the experience of families of children with disabilities based on internal experience and the results of over 21,000 household surveyed.

Please feel free to make additions or to comment.

We are looking forward to work with you.

Kind regards,

Erna van der Westhuizen

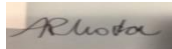Programmes Manager

Uhambo Foundation

SUPERVISOR/PROJECT LEADER/DISCIPLINE ACADEMIC LEADER

NB: PLEASE ENSURE THAT THE APPLICANT HAS COMPLETED THE ATTACHED CHECK **SHEET AND THAT THE FORM IS FORWARDED TO YOUR SCHOOL RESEARCH COMMITTEE FOR FURTHER ATTENTION**
DATE: ……………11/07/2016……………………….. **SIGNATURE OF SUPERVISOR/ PROJECT LEADER/DISCIPLINE LEADER** _____

RECOMMENDATION OF FACULTY RESEARCH ETHICS COMMITTEE/HIGHER DEGREES COMMITTEE

The application is (please tick):

- Recommended and referred to the Human and Social Sciences Research Ethics Committee for further consideration

- Not Approved, referred back for revision and resubmission

- Other: please specify:

NAME OF CHAIRPERSON:

_____SIGNATURE:_____

DATE ………………………………………

RECOMMENDATION OF UNIVERSITY RESEARCH ETHICS COMMITTEE (HUMAN AND SOCIAL SCIENCES)
NAME OF **CHAIRPERSON:_____SIGNATURE_____** **DATE...………………………………………**

CHECK SHEET FOR APPLICATION

PLEASE TICK

1.	Form has been fully completed and all questions have been answered	**x**
2.	Questionnaire attached (where applicable)	
3.	Informed consent document attached (where applicable)	**x**
4.	Approval from relevant authorities obtained (and attached) where research involves the utilization of space, data and/or facilities at other institutions/organizations	**x**
5.	Signature of Supervisor / project leader	**x**
6.	Application forwarded to Faculty Research Committee for recommendation and transmission to the Research Office	

UNIVERSITY *of the*

WESTERN CAPE

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: reneej@boothhosp.org

Revised: December 2015

<u>**INFORMATION SHEET: Families with special needs children**</u>

Project Title: Perceptions, challenges and coping strategies of families caring for children with special needs.

What is this study about?

This is a research project being conducted by Priscilla Matambanadzo at the University of the Western Cape for this study. The purpose of this research project is to explore the perceptions and coping strategies of families caring for special needs children.

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

You will be asked to participate in an interview. This research project involves making audiotape recordings of you. The recordings will be made in order to verify information during the study. You will be given a transcription of the data to verify that the information you gave is correct.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure confidentiality of the data collected:

(1)   Your name will not be included on the collected data
(2)   A code will be placed on the collected data
(3)   Through the use of an identification key, the researcher will be able to link your survey to your identity
(4)   Only the researcher will have access to the identification key.

To ensure your confidentiality, all transcribed data will be stored in locked filing cabinets; any electronic information will be stored using password – protected computer files. This data will not contain your particulars, it will be coded.

If we write a report or article about this research project, your identity will be protected.

This study will use focus groups therefore the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about families caring for children with special needs. We hope that, in the future, other people might benefit from this study through improved understanding of self - management.

This research may assist in decreasing the burden on an already financially stressed health system that operates on few resources. While also assisting the local population with autonomy, by sharing their experiences. The findings can facilitate research on this topic and assist with development of better programmers to support the family.

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?

This research is being conducted by Priscilla Matambanadzo from the Social work Department, at the University of the Western Cape. If you have any questions about the research study itself, please contact Priscilla Matambanadzo at Cape Town Child Welfare:

0216383127

priscillamatambanadzo@yahoo.com

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:

Prof Nicky Roman
Head of Department: CFS
University of the Western Cape
Private Bag X17
Bellville 7535

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17 Bellville 7535

chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: *to be inserted on receipt thereof from the applicable Research Ethics Committee*)

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: reneej@boothhosp.org

CONSENT FORM

Title of Research Project: Perceptions and coping strategies of families caring for children with special needs.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___   I agree to be audiotaped during my participation in this study.
___   I do not agree to be audiotaped during my participation in this study.

Participant's name………………………..

Participant's signature……………………………….

Date………………………