STRATEGIES OF PARENTS TO ENSURE THE HEALTH AND WELL-BEING OF THEIR CHILDREN WITH DISABILITIES: A HUMAN CAPABILITIES APPROACH

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ABSTRACT

Parents become the first teachers of the child and therefore the parent-child relationship is important for the development of a child. Parents who have a child with a disability are often more challenged than parents who do not. In South Africa, there are programmes and policies which are implemented to support parents or primary caregivers who have children with disabilities; however, there is no data or reviews available that provide information regarding the capability of parental strategies to ensure the health and well-being of their children with disabilities.

The aim of the study was to explore the strategies used by parents to ensure the health and well-being of their children with disabilities. This study used a qualitative methodological approach. Twelve parents with children who have a disability were recruited for interviews using purposeful sampling. In order to access parents who, have a child with a disability, the participants were recruited through organisations and schools. Interviews were conducted using semi-structured interview schedules that were conducted face-to-face with the participants. These interviews were audio-recorded and the participants consented to both participating in the study and having their interviews recorded.

The study was analysed using the 6 steps method of thematic analysis. Seven themes were identified, four of which were predetermined from the framework. These include (1) Capabilities of emotions, (2) Capabilities of affiliation, (3) Capabilities of bodily health, and (4) Capabilities of control over the environment. The three additional themes included (5) The kind of relationship parents have with their children with disabilities, (6) strategies and facilitators to ensure health and well-being, and (7) Barriers that hinder parents to ensure health and well-being of their children. These themes reflected the need to enhance the parents' abilities in all four capabilities in order to ensure that the strategies they currently use facilitate a good well-being for both the parent and child, and decrease the barriers that restrict them by providing parents with freedom and opportunities that will be valued by the parents in ensuring the health and well-being of their children with disabilities. All ethics were taken into consideration including informed consent, beneficence, anonymity, and confidentiality.

KEYWORDS

Parent

Child

Parent-child relationship

Parenting

Capabilities

Strategies

Disability

Wellbeing

Health

Human capabilities approach

DECLARATION

I, Abulele Hashe, hereby declare that this thesis *Strategies of parents to ensure the health and well-being of their children with disabilities: A Human Capabilities Approach*, is my own work, and that it has not been previously submitted for any degree or examination in any other university. All the sources used in this thesis have been acknowledged in text and in the reference list.

Abulele Hashe

Signature: Date:December 2020

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CHAPTER 1

INTRODUCTION

1.1 Background and Rationale

Parents are the first teachers of the child because the knowledge and the skills children acquire from them, during early childhood, eventually influence their development in their adulthood (Akinnawo, Ocheho, Adegbayi, 2013). There is evidence that suggests that the parent-child relationship creates the foundation for future health behaviour, adjustment, and well-being of the child (Davids, Roman & Leach, 2015; Rose, Roman, Mwaba & Ismail, 2017). Parent-child relationship creates the environment in which (1) there is the provision of care, nurturance, and protection, (2) children begin to acquire their beliefs, attitudes, values and behaviours considered appropriate to society (Ogwo, 2013), and (3) first relationships are established and may become the blueprint for other social relationships, as well as the basis for how decisions are made and how problems are solved (Botha & Booysen, 2013; Davids, Roman & Leach, 2015). However, raising a child with a disability cannot be compared to raising a typical developing child.

Parents raising children with disabilities also want to see their children reach their potential, play, and do most things that a child without a disability can do. They, as parents, want to be seen in communities as other parents and do what most parents are doing — working and being accepted by society. However, this is not the case with most parents. Parents and caregivers raising a child with a disability are likely to experience higher levels of burden, increased family risks, financial issues, and lower emotional well-being (Waters & Friesen, 2019; Ha, Greenberg & Seltzer, 2011; S'lungile, Ntinda, & Hlanze, 2015). Caring for children with disabilities can affect health and well-being of parents and have an impact on their families (Brannen & Heflinger, 2006; Shillitoe & Christie, 1990). This means that parents and caregivers raising children with a disability need support, which is often in the form of programmes and grants, to help them raise their children. On the other hand, their capabilities of being able care for their children also need to be adequately explored.

According to the Statistics South Africa (2014), based on the 2011 census in South Africa, there are 10.8% of children living with a disability between the ages of 5-8 years old, which is approximately 447.800 children. Furthermore, there are 4.1% of children with disabilities aged between 10-14 years old, which is about 161.800 children. Lastly, 2.6% of children with disabilities are between the ages 15-19 years old, which is about 108.700 children. Therefore, there are an estimated 718.300 children with disabilities in South Africa. However, that number does not include children younger than the age of 5 years old and children with psychosocial and neurological disabilities because of limited data (SSA, 2014). The statistics are based on people with moderate to severe disabilities in seeing, hearing, communication, remembering/concentrating, walking and self-care. Due to these large numbers of children with disabilities, most studies on disability, and parenting children with disabilities, have focused on the challenges parents experience, or their process of adjusting to raising a child with disability (S'lungile, Ntinda, & Hlanze, 2015; McNally & Mannan, 2013; Gardner & Harmon, 2002).

Parents raising children with disabilities experience financial difficulties because of expensive medication and the need to travel to and from health care services for their children. Parents lack the money to access health services and most of them do not have medical aids to assist them (Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010). McNally and Mannan (2013) suggest that these financial issues are a result of lack of employment as taking care of a child with a disability limits the chances of parents going out to look for jobs. Which in turn, this makes parents susceptible to financial challenges and struggle to do necessary things for both themselves and their children with disabilities (McNally & Mannan 2013).

They are not only struggle with finances, but some parents experience inadequate support from their family members, communities and even the government (Thoya, 2017). It has been said that the exposure to stressors at various points along the life course has long-term consequences for well-being, parents face emotional challenges from realizing that their child will be born with a disability which then continues until the child is old (Thwala, Okeke & Dludlu, 2018). Parents with children with disabilities endure stress the initial stage of searching for a diagnosis for the disability, which can take time to discover (Avieli & Band-Winterstein, 2017).

When the child gets diagnosed with a disability, it is said that they present with feelings of guilt, depression, anger, shock, denial, fear, self-blame, sorrow, grief, confusion, despair, hostility and may even emotionally breakdown (Heiman, 2002). Lastly, parents also struggle with trying to normalize the child's life and taking into consideration all the challenges that come with disabilities (Avieli & Band-Winterstein, 2017). On top of that, they also need to deal with the stigmatisation and discrimination that they get from communities regarding their children as realizing how the public treat their children can be emotionally challenging (Thwala et al., 2018).

The stigmas and discrimination that parents experience from their communities, because they have a child with a disability, come from health professionals and sometimes fathers who decide they do not want to part of the child's life (McHatton & Correa, 2005). Parents do not get enough support in their communities, or even by family members, due to existing stigmas or cultural beliefs about disability (Zuurmond, Mahmud, Polack & Evans, 2015). People in different communities in East Africa still have different beliefs about disability with some seeing it as evil while others believe it to be a gift from God (Stone-MacDonald & Butera, 2012). The main challenge facing parents is striking a balance between caring for their children and other activities in their daily lives. Caring for children with disabilities can affect the health and well-being of parents and that can have an impact on the family as a whole (Brannen & Heflinger, 2006; Shillitoe & Christie, 1990).

Most of the previous studies done on parenting a child with disability have focused on the experiences of parents and how they cope and adjust to their new reality. According to a survey done by Green (2007), 81 parents raising children with disabilities in Florida, the United States, suggested that meeting the personal, medical, educational and social needs of a child with a disability can be physically tiring and financially challenging especially in environments where poor service delivery and stigma exists. The challenges faced by parents are not necessarily accompanied by severe emotional distress as parents are also likely to feel emotionally rewarded, rather than saddened, by their parenting experiences.

A study done by Gona, Munga'la-Odera, Newton and Hartley (2010), in Kenya, Africa, showed that the arrival of the child with a disability in families severely impacts parent's expectations as parents. The study noted that parents raising children with disabilities face emotional distress, financial challenges, and the loss of dreams and future aspirations. This is because African societies place an importance on having children as they are expected to take care of parents during their old age. However, parents still need to make sure that their children are healthy and have good well-being regardless of what they face. That means that parents should have certain capabilities to be able to ensure the health and well-being of their children is intact.

The existing research on the care of children with disabilities focuses on the challenges parents and caregivers experience (Gona et al., 2010) as well as the support (grants and programmes) offered by the state (Thoya, 2017). Studies do not look at parent capabilities that they currently have in order to help their children develop and/or look at what restricts their existing capabilities have to be able achieve the functionings they value. Capabilities are not only the abilities inside a person but also the freedom or opportunities created by different factors from personal, social and environmental factors to function at their best (Hammell, 2015). External capabilities could include support groups that enhance the emotional capabilities of parents in dealing with the different challenges they encounter, or the providing of parents with proper homes that are conducive to raising a child with a disability. This will allow them to have freedom and opportunity to be, and do, what is valuable to them, which includes taking care of their children to be health and have a good well-being.

The current study's main aim was to explore the strategies used by parents to ensure the health and well-being of their children with disabilities through the lens of the human capability framework. Because previous research mainly focused on the challenges, it is important to further look at the strategies they used in order to work on decreasing those challenges. Looking at challenges and experiences only, and not how they are currently doing within those challenges to ensure the health and well-being of their children, will slow the process of actually dealing with those challenges. This study looks at the parent-child relationship, because of its importance on the development of children generally, and how the strategies parents use will eventually have an influence on the children's wellbeing (Akinnawo *et al.*, 2013). This study also looks at the barriers that hinder parents in ensuring health and well-being of their children, particularly the things that restrict parents' capabilities to achieve their valued functioning in taking care of their children.

1.2 Theoretical Framework

This study used capabilities approach as a theoretical framework for the researcher to draw viewpoints when analysing and interpreting data gathered. According to Robeyns (2003), Amartya Sen and Martha Nussbaum came up with the capabilities approach, which is also known as human development, in the 1980s as an economic theory that was an alternative to welfare economics. Capability approach is a broad normative framework for the evaluation of individual well-being, social arrangements and innovation of new policies about social change in society (Robeyns, 2003; Gupta, Featherstone & White, 2014). It was developed as a way of comparing quality of life and the formulation of basic political principles that can play a role in any human life, specifically focusing on the conception of the dignity of human beings and life that is worthy of that dignity (Nussbaum, 2003)

Nussbaum (2003) came up with 10 capabilities as central human capabilities that are basic requirements of a life with dignity (Nussbaum, 1997; 2003; 2007). These include *Life, Sense, Imagination and Thoughts, Practical Reasoning, Affiliation, Other Species, Play,* C*ontrol over One's Environment, Bodily Health, Bodily Integrity* and E*motions*. These capabilities are all distinct and indispensable components that are required to make an individual humane and have a life of dignity (Nussbaum, 2003). This study only focused on four capabilities: *Bodily Health, Affiliation, Emotions,* and *Control over One's Environment*. These four were chosen because most challenges facing parents raising children with disabilities primarily affect these capabilities.

Capability approach has two core concepts: capabilities and functionings. According to Mitra (2006), functioning is an activity/something a person does while capabilities are 'practical opportunities'. Functionings are activities, being and doings which are valued by an individual and capabilities are practical freedom and opportunities that a person has, or is provided with, to achieve functionings that they see as valuable in order to have a humane life (Nussbaum, 1997, 2003). Capability approach acknowledges that human beings are diverse, whether with/without disabilities, parents raising children with disabilities or not. The approach sees the need to understand that people encompass different life situations and circumstances, which require them to have different resources, freedoms and opportunities to convert them into desired and valued functionings (Alkire, 2008).

Furthermore, Capability approach highlights the importance of human diversity in the evaluation of people's relative advantages or disadvantages (Alkire, 2008). This entails the evaluation of disability in relation to how many resources/freedom and opportunities are distributed to ensure equality in terms of justice (Alkire, 2008). From a parent's perspective, parents raising children with disabilities experience challenges on those specific capabilities, therefore looking at the strategies they use will help to understand how they can be developed to strengthen their capabilities and ensure the health and well-being of their children with disabilities.

1.3 Problem Statement

Worldwide, there are 93 million children, aged 0-14 years old, with moderate disabilities and 13 million children with severe disabilities (WHO, 2011). In South Africa, there are 718.300 children with disabilities from the ages of 5 years to 19 years old (SSA, 2014). This shows the prevalence of children with disabilities both national and international. All of these children need to have parents to take care of them and to have a relationship with their parents or caregivers. A relationship between a parent and a child builds is crucial as it builds a foundation for the future behaviour, health and wellbeing of a child (Davids et al., 2015). However, there are many challenges faced by a parents who are raising a child with a disability (Tigere & Makhubele, 2019).

Studies done on children with disabilities show that parents raising children with disability are more prone to increased risks of emotional well-being and financial difficulties (Ha, Greenberg & Seltzer, 2011). The challenges have an influence on parents — especially those parents who are less resilient or who lack informal and formal sources of support — and that affects whether they are able to take care of their children to the best of their abilities or not (Gupta et al., 2014). Previous studies done on parenting a child with disability mostly focus on the challenges parents experience. For instance, a study done by Gona et al. (2010) revealed that parents raising a child with a disability are faced with poverty, stress and increased responsibility. Studies have clearly highlighted the challenges faced by parents, but no studies have reported on what the parents do to ensure that, regardless of the challenges, their children are still well taken care of.

This study explored the strategies used by parents to ensure the health and well-being of their children. It has used four capabilities from the human capability approach as a framework to assess parent capabilities. In doing so, this study aimed to close the gap that exists within studies on parenting and disability that do not look at their capabilities. This study looked at the strategies parents use, to explore them and see whether the strategies help or hinder parents from decreasing the challenges they face when raising children with disabilities. Looking at challenges and experiences only, and not also focusing on how they are currently making means within those challenges to ensure the health and well-being of their children, will slow the process of actually dealing with the challenges. Dealing with them, by finding ways to enhance the capabilities of parents, will ensure the health and well-being of their children with disabilities.

1.4 Research Questions

1. What are the strategies used by parents to ensure the health and well-being of their children living with disability?
2. What is the nature of the relationship between the parent and child with disability?
3. What are the barriers and facilitators that parents face when caring for children with disability that enhance the parent-child relationship?

4. How do parents use their capabilities (bodily health, emotions, affiliation and control over one's environment) to ensure health and well-being of their children?

1.5 Aims and Objectives

1.5.1 The Aim of the Study

The aim of the study was to explore the strategies used by parents to ensure the health and well-being of their children living with a disability.

1.5.2 The Objectives of the Study

Thus, the objectives of this study were to:

1. Explore the parent-child relationship;
2. Explore the strategies used by parents to ensure the health and well-being of their children living with a disability;
3. Explore the barriers of health and well-being experienced by parents in caring for their children living with a disability;
4. Explore how parents utilize their capabilities of (bodily health, emotions, affiliation and control of their environment) to ensure the health and well-being of their children with disabilities.

1.6 Significance of the Study

It is evident that parents raising children with disabilities face emotional distress, financial challenges, and lost dreams/future (Thwala, Ntinda, & Hlanze, 2015). However, parents still need to make sure that their children are healthy and have good well-being regardless of what they face. That means parents should have certain capabilities to be able to ensure the health and well-being of their children. Exploring the strategies, they used will help to further understand parents and their efforts to ensure health and well-being of their children with disabilities. To understand what parents are currently having in terms of their capabilities to achieve functionings and what they still need in order to ensure that.

This research hopes to allow parents to see where they need to strengthen and improve their parenting by looking at capabilities they lack and still need to work on. The research will not only help parents but it also hopes to assist the community at large as it educates people in, and also other institutions like schools and NGOs, to understand and work hand-in-hand to help parents develop capabilities that will allow them to achieve functionings they value and also ensure health and well-being of their children in the process. The study hopes to also bring the government and policy maker into light in terms of understanding that parents raising children with disabilities are not faced with the challenges that parents with typical developing children face. Therefore, they need to be provided with freedom, opportunities and resources that are specifically focused on enhancing their lives in order for the parents to have better strategies to ensure health and well-being of their children with disabilities. The study hopes to add to the body knowledge regarding the field of disability and the field of human capability theory in both South Africa and globally.

1.7 Ethics

To be able to include participants for interviews it is important for the researcher to get ethical clearance as a permission to conduct the study. Ethics approval was obtained from the Human Social Sciences Research Ethics Committee of the University of the Western Cape. To get permission to access participants, the researcher contacted the gatekeepers from various organisations and schools for disabled children to ask for permission to recruit parents to participate in the study. Before conducting the research, the researcher informed the participants what the study was to entail, the nature of the study, and their right to withdraw at any time. The researcher also noted that participation in this study was voluntary and that non-participation would not be held against them, they will have access to debriefing when needed. All this is in the Information Sheet which participants were given to read — see APPENDIX C.

The participants signed a consent form before participating and provided verbal consent. Once a sample was identified, the following ethics were taken into consideration: **Informant consent** — the researcher made sure that the participants entered the study voluntarily, understanding what was expected from them and the potential consequences of the study. Participants were provided with written and verbal informed consent before they participated in the study. An informed consent has information about the study, what is expected from the participants and a space to sign whether the participants agree or not to participate. Participants were given a chance to ask any questions they might have regarding the study, and an informed consent was provided in consideration of their preferred language (See Annexure B). **Beneficence** was assured by informing participants that they will not be harmed or deceived in any way. They were also allowed to withdraw from the study if they wanted to and, in case they needed counselling due to the research, a counsellor would be provided.

Anonymity was ensured by allocating pseudonyms to each of the participants in order masking their personal details. To remain anonymous, participants were given numbers between 1 and 12 (Creswell & Tashakkori, 2007). The participants' identity was hidden in all written and verbal reports of the results, as well as in informal discussions with colleagues and fellow students. **Confidentiality** was maintained through the protection of the participants' identity by using pseudonyms in all writing reports and in conversations with colleagues. The protection of data was ensured as all data was secured on a computer with a password that could only be accessed by the researcher. Finally, the interviews were in private spaces that the participants chose.

1.8 Definition of Terms

Parent-Child Relationship: the quality of the emotional connection between child and parents (mother and father or significant parental figure) and the degree to which this connection is mutual and sustained over time (Lezin, Rolleri, Bean, & Taylor, 2004).

Disability: disability is an umbrella term for impairments, activity limitations and participation restrictions. It refers to the negative aspects of the interaction between an individual (with a health condition) and their contextual factors, including environmental and personal factors (WHO, 2011). This study does not focus on a particular disability but includes all kinds of disabilities.

Parent: biological, foster or adoptive mother and/or father responsible for the care and protection of a young child (The National Integrated Early Childhood Development Policy, 2015:13)

Child: according to the Children's Act 2005, children are any person under the age of 18.

Parenting: to socialize, teach, and promote the physical and emotional development of a child from infancy to adulthood (Antonopoulou, Hadjikakou, Stampoltzis, & Nicolaou, 2012). It is also described as the act of raising a child rather than the biological relationship, which is usually done by the biological parents of the child in question (Antonopoulou et al., 2012)

Capabilities: a person's abilities. These are not solely the abilities inside a person but also the freedoms or opportunities created by personal abilities, resources, political and social environment (Hammel, 2015).

Strategies: the course of action to deal with a situation (Mintzberg, 1987)

Human Capability approach: was developed as a framework to analyse different concepts in welfare and economics. This includes standards of living, personal well-being, quality of life, and poverty (Mitra, 2006)

Well-being: well-being is how individuals perceive the amount of being content in their lives across the domains of home life, school, managing situations, and encounters with people (Cripps & Zyromski, 2009)

Health: According to the World Health Organization (WHO), health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 1997).

1.9 Outline of Chapters

The following is a brief outline of the chapters of the study:

Chapter 1 is the introduction of the study, strategies of parents to ensure health and well-being of their children with disabilities; A Capabilities Approach. The chapter provides an overview of the full thesis, giving the background and rationale of the study, describing the aims and objectives, and stating the problem and ethical consideration that were followed in the study. The chapter briefly introduces the theoretical framework on which the study is formulated, the research methods applied and the significance of the study.

Chapter 2 is the theoretical framework of this study. This chapter presents the theoretical framework that guides the study. The content in this chapter includes an exploration into capability approach and its core concepts. The chapter focuses on four of the ten human capabilities by Martha Nussbaum — emotions, affiliation, control over the environment, and bodily health. These four capabilities are the main primary focus of this study. This chapter also touches on parents and capabilities as well as disability and capabilities.

Chapter 3 is the literature review of the study. This chapter provides critical insight into the relevant evidence available concerning this study. Content in this chapter includes the definition of disability, causes of disability, types of disabilities, the prevalence of children with disability in South Africa, nature of parent-child relationship, and barriers and facilitators that influence parents in ensuring health and well-being of their children. It also explores the strategies parents use in raising their children.

Chapter 4 is the methodology of the study. This chapter presents the methodological processes of the study. It also outlines the aims and objectives of the study. The methodological processes include the research approach used when conducting the study, the research design used, and the data collection tools that were used, process of data collections, and information on the population and sampling of the study. Finally, this chapter also contains the data analysis and all ethical considerations addressed during the study.

Chapter 5 is the findings and discussion of the study. In this chapter, the results of the study are presented and discussed. They are integrated with previous studies done on the topic and theoretical framework from chapter 2 is also linked as it was used to guide the study. In this chapter, seven themes emerged and were discussed. They include four predetermined themes (capabilities of emotions, capabilities of affiliation, capabilities of control over the environment, and capabilities of bodily health) and three additional themes: barriers that hinder parents when ensuring the health and well-being of their children, strategies/facilitators parents use to ensure health and well-being of their children, and the kind of relationship parents have with their children.

Chapter 6 is the conclusion and recommendations of the study. This chapter concludes the study, presenting a summary of the themes that emerged from the study, and the limitations of the study. It also offers recommendations for future research, policies, and parents.

Chapter 2

Theoretical Framework

2.1 Introduction

In this chapter, an extensive discussion on capabilities approach and human capabilities (based on Nussbaum's 10 capabilities) is provided. The 10 capabilities developed by Nussbaum (1997; 2003; 2007) include *Life, Sense, Imagination and Thoughts, Practical Reasoning, Affiliation*, *Other Species, Play, Control Over One's Environment, Bodily Health,* B*odily Integrity* and E*motions.* While the discussion will briefly address all the capabilities, it will mostly focus on Bodily Health, Emotions, Affiliation and Control Over one's Environment.

2.2 Capability Approach

Capability Approach is pioneered by the economist and philosopher Amartya Sen (Robeyns. 2007). More recently, capability approach has been significantly developed by the philosopher Martha Nussbaum (Robeyns, 2007). Amartya Sen developed capabilities approach (which is also known as Human development) in the 1980s as an economic theory that was an alternative to welfare economics (Robeyns, 2007).

Capability Approach is a broad normative framework for the evaluation of individual well-being, social arrangements, and the innovation of new policies regarding social change in society (Robeyns, 2003; Gupta, Featherstone & White, 2014). Sen argues that in social evaluations and policy design, the focus should be on what people are able to do, and be, and on removing obstacles that hinder their lives to have more freedom to live the kind of life which they find valuable (Robeyn, 2007). In capability approach, between the means and ends of well-being and development, only the ends have the basic importance. Means are a driving force to reach a targeted goal of increased well-being and development (Robeyn, 2007). This approach is concerned with different aspects of individuals' lives, including their health, education, and the support they enjoy from people around them. It is also concerned with what people can do (opportunity to achieve valuable combinations of human functionings), such as being able to work, raise a family, travel, or be politically active in issues that concern them (Robeyns, 2017).

Capability Approach cares about people's real freedoms to do the aforementioned things as well as the level of wellbeing that they will reach when choosing from the options open to them. Since 1990, The Capability Approach has been embodied in the annual Human Development Reports of the United Nations Development Programme (Nussbaum, 2007). The capability approach is used in different fields such as in human development, welfare economics, social policy and political philosophy (Robeyns, 2017). Robeyns (2003) states that, capability approach is used to evaluate a wide variety of aspects of people's well-being, such as individual well-being, inequality and poverty.

According to Gupta et al. (2014), capability approach directly focuses on the quality of life that individuals are able to achieve, considering not just resources but also the valued things people are able to do or to be as a result of having the resources they need. Capability approach, according to Nussbaum (2007), is a species of a human rights approach. The goal of capability approach is to ensure people are capable of functioning in a variety of areas of central importance (Nussbaum, 2007).

Furthermore, Capability Approach has an influence on the human rights policies and Nussbaum (2007) sees her capability approach as a version of human rights theory (Robeyns, 2017; Harnacke, 2013). Human rights theories and capability theories are for the enhancement and protection of human beings (Harnacke, 2013). Human rights are the rights each human being is entitled to and they aim to protect people from harm that could be inflicted by others — this includes the deliberate actions done by other people and the failure to protect human rights caused by institutional structure (Robeyns, 2017). Just like the capability approach, human rights protect people and tries to ensure that they have dignity. Capabilities approach believes that society should provide certain capabilities for everyone, real opportunities, at an appropriate threshold level for everyone regardless of how diverse they are (Harnacke, 2013). Robeyns (2017) argues that some human rights — not necessarily all of them — can be viewed as capabilities.

2.3 Core Concepts: Functionings and Capabilities

Functionings and Capabilities are the core concepts in capability approach. According to Mitra (2006), functioning is an activity — something a person does — and capabilities are 'practical opportunities'. Furthermore, Robeyns (2003) states that capabilities are a person's real freedom or opportunities to achieve functionings while functionings are the beings and doings that constitute human life and are central to our understanding of ourselves as human beings. Functionings can involve some quite basic characteristics such as being well-nourished, being in good health, and receiving an education or they may involve quite complex activities. It can also include states of being such as having self-respect, the preservation of human dignity, and participating in social and community life. A person's capability refers to the different combinations of functionings a person can choose to have; 'In this sense the capability of a person corresponds to the freedom that a person has to lead one kind of life or another' (Reindal, 2009). In this study, a parents' functionings may be being emotionally strong and being nourished, while capabilities to those functioning may be attending support groups for parents raising children with disabilities or having enough healthy for both the parents and their children.

2.4 Martha Nussbaum's 10 Human Central Capabilities

Both Sen and Nussbaum use capabilities to provide a measure of a person's quality of life but Nussbaum took her approach further, and created a list of capabilities. The list is grounded in Aristotelian thinking about human need and flourishing (Leahy, 2012). Nussbaum's approach is based on the idea that people are free and dignified beings. According to Nussbaum (2007), producing capabilities requires material and institutional support.

Capability Approach was developed as a way of comparing quality of life and for the formulation of basic political principles that can play a role in any human life (Nussbaum, 1997, 2003). Nussbaum developed 10 human central capabilities as central requirements of a life with dignity and they note that human central capabilities are the basic capabilities to which every human being is entitled (Nussbaum, 1997; 2003; 2007). Curtis and Cosgrove (2017) argue that there is considerable room for disagreement when identifying the basic central capabilities due to how societies differ and value different things. Hence, there are some acceptable differences among cultures and individuals regarding what constitutes a valuable human life.

Nussbaum (1997) endorsed a specific list of the central human capabilities as a comparative quality-of-life measurement and for the formulation of basic political principles that can play a role in constitution. This list was created with the aim of focusing more on the conception of the dignity of human beings and the idea that life is worthy of that dignity (Nussbaum, 2003). Nussbaum (2003) believed that this list has human capabilities that are basic requirements of a life with dignity. These capabilities are all distinct and indispensable components and are required to both make an individual humane and allow them to have a life of dignity.

Nussbaum (1997) states that the list consists of human capabilities that are of central importance in any human life. Societies and government are supposed to use these human capabilities as general goals to achieve, as human capabilities work on the account of fundamental rights of every human being (Nussbaum, 2007). Nussbaum believes that a society, that does not aim to apply these human capabilities to its citizens, robs its people of having a fully just society. Human capabilities are supposed to be held as an important basic requirement to each person, regardless of their role in society is. The list can be challenged and remade, and it does take biology into account as an element of human beings.

The following list is an attempt to summarize the empirical finding of a broad and ongoing cross-cultural inquiry and it is the current version of Nussbaum's list of human capabilities (Nussbaum, 2003).

The Central Human Capabilities

1. **Life:** Being able to live to the end of a human life (of normal length) and not dying prematurely, or before one's life is so reduced as to be not worth living. Life is a central capability because it is a basic human entitlement to have normal length time and have a life that is worth living. The principle on life capability relates to life expectancy, asserting that no one should have to accept a life of seriously foreshortened mortality (Curtis & Cosgrove, 2017). An example of this includes a life that is not worth living due to how one is treated, or being under risks that could prematurely end one's life.

2. **Bodily Health:** Being able to have good health (including reproductive health), to be adequately nourished, and to have adequate shelter. Bodily health does not just focus on the absence of diseases. Rather, to be healthy holistically in all aspects of the body, mind, and soul, one should be in an environment that is safe for an individual. Bodily health capabilities relate to food security and shelter security, and the idea that no one should have to accept a life that is susceptible to disease (Curtis & Cosgrove, 2017).

3. **Bodily Integrity:** Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction, and having choice in matters of reproduction. Bodily integrity capability is about one's right to have control over, and security for, his or her own body (Nussbaum, 2007).

4. **Senses, Imagination, and Thought:** Being able to use the senses to imagine, think, and reason, and to do these things in a ''truly human'' way — a way informed and cultivated by an adequate education including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experience and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways that are protected by guarantees of freedom of expression with respect to both political and artistic speech and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain. (Nussbaum, 2007)

5. **Emotions :** Being able to have attachments to things and people outside ourselves and to love those who love and care for us as well as to grieve at their absence. In general, this means to love, to grieve, and to experience longing, gratitude, and justified anger. It also means not having one's emotional development blighted by fear and anxiety. Emotion capabilities connect to the freedom that everyone must have to form relationships as well as the freedom of association (Curtis & Cosgrove, 2017). Supporting this capability means supporting forms of human association that can be shown to be crucial in human development.

6. **Practical Reason:** Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. Practical reasoning capabilities means a

broadly construed intellectual freedom which includes freedom of religion. Every human should be able to think for him or herself, and to make reasoned choices about the life one leads (Curtis & Cosgrove, 2017).

7. **Affiliation:** Being able to live with, and toward, others, to recognize and show concern for other human beings, and to engage in various forms of social interaction including being able to imagine the situation of another. The protection of this capability means protecting institutions that constitute, and nourish, such forms of affiliation, as well as protecting the freedom of assembly and political speech. It also includes having the social bases of self-respect and non-humiliation and being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination based on race, sex, sexual orientation, ethnicity, caste, religion, and national origin. (Nussbaum, 2007)

8. **Other Species:** Being able to live with concern for, and in relation to, animals, plants, and the world of nature (Nussbaum, 2007).

9. **Play:** Being able to laugh, play, and enjoy recreational activities. All human being are entitled to play, and time to themselves to enjoy activities that are fun to them. Playing is not restricted to age as anyone can play. (Nussbaum,2007)

10. **Control Over One's Environment:**

- Political: Being able to participate effectively in political choices that govern one's life, having the right of political participation, and having protection over free speech and association. (Nussbaum, 2007)

- Material: Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others, and having the freedom from unwarranted search and

> seizure. In regard to work, this means being able to work as a human being. It also means exercising practical reason and entering into meaningful relationships of mutual recognition with other workers. (Nussbaum, 2007)

This study only focused on four of the aforementioned capabilities — *Bodily health:* being able to have a good health; *Affiliation:* being able to live with others showing concern for other people, and being able to be treated with dignity; *Emotions:* being able to have attachment to things and people outside ourselves, and the ability to grieve; and *Control over one's environment:* being able to participate in political choices that affect one's life and having equal rights to seek employment. Parents raising children with disabilities face different challenges than other parents, challenges ranging from psychological and financial issues to social challenges (Tigere & Makhubele, 2019). Focusing on these four capabilities does not discard the importance of other capabilities. Rather, these four were chosen because most challenges faced by the parents stem from the lack of these specific capabilities.

2.4.1 Affiliation

Affiliation capabilities refers to the freedom of association that one must have and is not only perceived in political terms in the form of freedom to form, or join, political parties or other societal organizations (Curtis & Cosgrove, 2017). It is also about sociability, the capability to have a variety of social relations, and to do so without being discriminated against because of one's race, gender, sexual orientation, ethnicity, caste, religion or any other category. According to Rugoho and Maphosa (2016), parents of children with disabilities tend to experience isolation and be neglected by their relatives and the government. That isolation and neglect by relatives, friends and government challenges their capabilities of having affiliation, being able to live with others and show concern for other people. The discrimination and stigma parents raising children with disabilities get from their communities (Rugoho & Maphosa, 2016), highlights how parents and their children are not being treated with dignity in societies. Furthermore, this isolation does not only affect their affiliation capabilities but also their emotions. To help parents manage and be able to ensure health and well-being of their children, it is important to know that they have enough capabilities of affiliation, which include support, love and respect from the people close to them, society and the government.

2.4.2 Emotion

According to Nussbaum (2003), emotions shape our mental and social lives and affect the way people react to situations as their reactions are influenced by their emotions behind the thoughts that one might have about a situation. The thoughts parents have about their children affect their mental and social lives and this is because of the value and importance their children have (Morris, Silk, Steinberg, Myers & Robinson, 2007). Emotions are forms of evaluative judgment that ascribe to certain things and people (Nussbaum, 2003). They always involve a thought of an object or a person combined with a thought of the object's importance in that sense, they always involve appraisal or evaluation. Emotions include grief, fear, love, joy, hope, anger, gratitude, hatred, envy, jealousy, pity, and guilt.

According to Nussbaum (2003), emotions are not just the driving force that powers the psychological mechanism of individuals, but they are a highly complex and messy part of the individual. Thus, a theoretical account of emotions is not only about large consequences for the theory of practical reason, for normative ethics, and for the relationship between ethics and aesthetics. Rather, theoretical account of emotions also has consequences for political thought as well as for understanding the relationship between various conceptions of humans and emotions which informs our deliberations about how politics might support people to flourish.

Nussbaum (2003) states that, if we think of emotions as essential elements of human intelligence rather than just as supports or props for intelligence, we will have strong reasons to promote the conditions of emotional well-being in a political culture, meaning that, without emotional development, a part of our reasoning capacity as political creatures will be missing (Nussbaum, 2003). Raising a child with disability affects parents' psychological well-being and some parents adapt to the child's disability while others suffer post-traumatic symptoms and increased mental health risks (Koivula, Kokki, Korhonen, Laitila & Honkalampi, 2019). Emotional well-being needs to be promoted, there is a need to have structures that empower emotional development, and not see emotions as just secondary but as part of an individual. Parents need support from relatives and the government to strengthen their emotion capabilities and ensure the emotional well-being of their children.

2.4.3 Bodily Health

According to Nussbaum (2003), bodily health focuses on 'good health' and she addresses the importance of nutrition, housing, and reproduction health. Bodily health is not just the absence of diseases. She states that every human being should be able to have good health, be adequately nourished, have adequate shelter, and have productive health to be able to flourish in life (Nussbaum, 2003). If capabilities are freedom and opportunities for a person to be, and do, what they see as being worthy, and of value, then mental and physical suffering, or dysfunctions, can be seen as restrictions on a person's opportunities and freedom (Curtis & Cosgrove, 2017). Those deficits of freedom and opportunities might prevent a person from preventing or getting treatment for diseases (Curtis & Cosgrove, 2017).

Parent's bodily health is also sometimes compromised when raising a child with disability. In a study conducted by Rugoho and Maphosa (2016), parents raising children with disabilities reported experiencing fatigue and anxiety which resulted in them not being able to do what they would like to as parent to their children. Parents raising children with disabilities do not only suffer from physical and mental difficulties but also financially challenges. These financial challenges restrict them from getting food and other necessities that provide them with enough nourishment to have a life that is valuable to them and their children.

2.4.4 Control over one's Environment

Environmental conditions are important as they directly impact the opportunities available to people (Curtis & Cosgrove, 2017). They make a range of basic capabilities, for instance; human beings depend on natural environment for basic needs like water and food to have life, which is the first central capability on Nussbaum's first list of basis capabilities. Curtis and Cosgrove (2017) presents a minimum of 10 basic environmental entitlements that constitute basic justice and whose absence can define poverty. These include being able to be adequately nourished, being free from disease, living in an environmentally clean and safe shelter, having adequate drinking water and clean air, having the energy to keep warm and clean, using traditional medicine, coping with extreme natural events, making sustainable management decision that respect natural resources, and using natural elements for cultural and spiritual practices (Curtis & Cosgrove, 2017).

Only one of the environmental entitlements listed by Curtis and Cosgrove (2017) is similar to Nussbaum's list of human capabilities about living in a clean and safe shelter. According to Nussbaum, control over the environment capabilities means that people should be able to hold property and thus have a safe shelter. Capabilities of control over one's environment constitute of two aspects, having control over political and material issues that affect livelihood of a person. Everyone should be able to participate in political choices that govern their lives, hold property and have a right to be employed (Nussbaum, 2003). The absence of these basic capabilities can make an individuals' life not worthy as they would experience poverty due to lack of freedom and opportunities to have better lives. From the capabilities perspective, a key aspect in the poverty–environment relationship is not having freedom in terms of their environment, and how depended people are with it (Curtis & Cosgrove, 2017). When people do not have a voice over political issues that govern their lives, they are most likely to be abused and not treated well. Also if people do not have property shelter and means to gain money to support themselves they are susceptible to getting disease, experience hunger and poverty.

Capability approach is concerned with people's freedom to be, and do, what people view as valuable (Nussbaum, 2003). People need to have control over their lives. This study looks at this capability because parents raising children with disabilities often experience financial struggles. Parents experience financial struggles because of unemployment as they have limited time to look for jobs because they constantly need to take care of their child's needs (McNally & Mannan, 2013). This shows how they do not have the freedom to control their lives and are rather dependent on what is readily available and given to them by the government.

These four capabilities touch on many challenges that most parents experience. Parents in South Africa experience these challenges because of lack of resources and services at their disposal (Tigere & Makhubele, 2019), which then hinders how they ensure the health and well-being of their children. Focusing on these four capabilities will benefit parents of children with disabilities because they will be able to see both the strategies they use and where they can improve, or strengthen, the strategy in order to decrease the challenges they face and ensure the better health and well-being of their children.

The capability approach maintains that resources are inadequate indicators of wellbeing because human beings have different needs and require different resources to convert into functionings (Gundersen, 2012). The government and policy makers can also develop an understanding about what they need to focus on in terms of providing suitable services for parents raising children with disabilities to achieve better functionings.

2.5 Capabilities and Disability

Harnacke (2013) states that, capabilities approach provides a good starting point from which to analyse disability. While most social contract theories assume that individuals in societies are free, equal, and independent with some sort of idealized rationality, this is not the case in most societies and the capability approach avoids this idea as it believes that a society does not consist of independent citizens with the same needs and abilities. People with physical or mental disabilities are often not taken into consideration by theories and when a theory does consider them, they are often regarded as being 'excessively needy, deficient in skills, talents and personal attributes' (Harnacke, 2013).

Capability approach takes people with disabilities into account by acknowledging that all people differ in their abilities to convert resources into functionings. Harnacke (2013) provides an example of this regarding the 10th human capability on Nussbaum's list — control over one's environment (the ability to participate effectively in political choices that govern one's life). He states that people without disabilities have laws that protect, and allow, them to engage with their political rights, however it is different for people with disabilities. For example, a person who is blind would need support from the government to acquire voting material that is in braille in order to be able to vote. This should be the case to parents raising children with disabilities also. Parents raising children with disabilities require an environment in which they can atleast have control over, especially on things that affect health and well-being of their children. They need to be empowered on emotion and affiliation capabilities, to be emotionally able to deal with the challenges they experience. Lastly, having control over their environment, means freedom to even provide for their families and striving in having bodily health capabilities.

In South Africa, people with disabilities get grants from the government (Thoya, 2017), however this should not be the only support they receive. Capability approach advocates for freedom and opportunities to be available for people with disabilities to be able to do, and be, what they want. It acknowledges that people are different and that if a person with a disability was provided with enough resources (not only grants), they could do anything a person without a disability can do (Harnacke, 2013). Parents need more than just financial help, but capabilities that will sustain them for some time.

An advantage of the capabilities approach is that, by focusing from the start on what people are actually able to do and be, allows the drive to address inequalities that people suffer from inside the families and societies, the inequalities in resources and opportunities, educational deprivations, the failure of work to be recognized as work, insults to bodily integrity (Nussbaum,2003).

2.6 Capabilities and Parents

According to Hartas (2014), functionings are what people achieve and capabilities are the ability to achieve those functionings. He states that, with children's well-being, parents' functionings refer to parental behaviour and practices that support children to live a life they value while acknowledging the existence of social and structural constraints. Whereas capability refers to parents' ability to operate within these constraints and convert the real opportunities they are afforded into valued functionings and ultimately exercise the freedom to choose among possible lifestyles (Hartas, 2014).

Hartas (2014) also adds that functionings are connected to the different living conditions around individuals which may apply to parents and the way in which they parent their children. Educated parents may be in a better position to offer health and well-being to their children at home as well as create a space that is conducive to their development (Hartas, 2014). Other parents may struggle due to a lack of capabilities such as not having enough knowledge or resources to ensure their children's health and well-being. Poverty can also have a direct influence on parents who are raising children with disabilities and parents who are less resilient or who lack informal and formal sources of support (Gupta et al., 2014).

According to Hartas (2014), capability approach contributes to understanding parenthood and its influence on child development. It acknowledges that functionings, or what parents achieve during their interactions with children, are bounded by their living conditions and the parents' ability to convert opportunities into functionings. It highlights the important role that parents and society play in supporting children's health and well-being. It also allows parents to be able to exercise their will in deciding what constitutes a valued activity or state of being while acknowledging human diversity and different living conditions. Capabilities like control over one's environment, emotions, affiliation and bodily health are necessary things to have as a parent raising children with disabilities. They provide parents the freedom to be fully available and strengthen parent-child relationship. They ensure that parents provide the best care possible regardless of their financial status.

2.7 Capabilities of Parents

Gundersen (2012) argues that it is important in human development for parents taking care of their children with disabilities to maintain their positive conception of self. He states that self-concept refers to the continuity of an individual's experience of self in different situations. Those experiences of self do not have to all be perfect and they are not static. Rather, they are related to what influences our lives, all of which are modified through dynamic relationships.

A person's self-concept is strongly influenced by the values and attributes society places on his or her role, status or relationships (Hoeve, Jansen & Roodbol, 2014). Parents with children who have disabilities might experience a change of self-concept when they find out that their child will have a disability (Gundersen, 2012). To maintain a positive sense of self and life that is worth dignity, Nussbaum (2007, 1997) argues that people need to live according to the 10 human capabilities. This study focuses on four of the ten capabilities, not because the others are not important (they are all important) but because the challenges that come with being a parent that is raising a child with disabilities mostly fall within these four capabilities, which then affect their self-concept and how they ensure the health and well-being of their children.

Parents raising children with disabilities need to be able to have good health, which requires a number of functions like eating health and being psychologically and emotionally well. They must be able to have affiliations with other people, show concern for other people and be treated with dignity. They must be able to show emotion, have attachment to things and people outside themselves, to grieve; and have control over their environment by participating in political choices that affect their lives and have equal rights to seek employment (Nussbaum, 2007). These are basic abilities that parents should have to enjoy a life with dignity and meeting these basic abilities can help them in ensuring the health and well-being of their children.

2.8 Critiques of the Capability Approach

Capabilities approach has received some criticism from some scholars (Curtis & Cosgrove, 2017). One criticism that is sometimes made is that the capability approach is too individualistic as it focuses on the freedom of an individual and not groups. However, to dismiss this criticism, Sen emphasised that capabilities are not incompatible with application to groups or social structures (Robeyn, 2017). Rather, the approach acknowledges that social structures and groups can use the approach in conversations to improve individual’s capabilities and functionings in the norms or in formal state institutions.

The second criticism that the capabilities approach receives is based on the difficulty in agreeing on the set of basic capabilities. Different people, in different societies, have different values and ideas around what worthy living is and, therefore, one capability might be less important in one society while it is of a great value to another due to cultural norms (Curtis &

Cosgrove, 2017). This difficulty in agreeing on the set of basic capabilities makes the approach difficult to operationalize. Lastly, it has been alleged that the capabilities approach, and more particularly Nussbaum's list of capabilities, is a product of imperialistic western thinking. Curtis and Cosgrove (2017) state that Nussbaum's thinking ignores, and excludes, non-western views of a good life and valuable freedom. However, Curtis and Cosgrove (2017) state that those claims are rejected by Nussbaum, and she argues that many CA theorists are from non-western societies for them to exclude and ignore non-western views of a life worth to be lived in non-western regions.

2.9 Conclusion

The capability approach holds that resources are inadequate indicators of wellbeing because human beings have different needs and resources to convert them into functionings. Two people might have the same resources but differ in the way in which those resources serve them. Children with physical disabilities need their parents to ensure their health and well-being, however, parents also need to make sure that their lives are worth living. For parents to do their role well they also need to be helped to develop their capabilities. The government, and the community as a whole, should offer more than just grants and should create an environment that allows parents to do, and be, what they see as valuable to themselves. This means that they should have an environment that is not taking advantage of them and but one that offers different kinds of economic and practical support with the intention of easing parents' caregiving burdens, and promoting equal opportunity for all parents to provide their children with optimal development.

CHAPTER 3

LITERATURE REVIEW

3.1 Introduction

This chapter provides critical insight into the relevant evidence available concerning this study. Content in this chapter includes the definition of disability, causes of disability, types of disabilities, and the prevalence of children with disability in South Africa. It will also cover the nature of parent-child relationship, barriers and facilitators that influence parents in ensuring health and well-being of their children, and the strategies parents use in raising their children.

3.2 Disability

Disability is a broad term, and there are many definitions associated with it. The definitions vary according to societal norms, organization, medical entities and governmental agencies that address disability issues. According to the World Health Organization, the term *disability* is defined as:

> …the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). (WHO, 2011)

Environmental and personal factors may present barriers for people living with health conditions to both function and participate in activities that the person wants to participate in (Mitra, Posarac & Vick, 2011). This definition combines disease, injuries, health disorders and other health related conditions into one as health conditions, because in interaction with individual's contextual factors they can all result in impairment and limit an individual. By removing the barriers, persons with health conditions can be enabled to function and participate.

Peek and Stough (2010) define the term as a physical and mental impairment that significantly limits one or more of the major life activities of an individual. Both definitions imply that being disabled is when a person has an impairment that limits them to participate in various activities. Disability results from the interaction between a person's impairments and attitudinal and environmental barriers that hinder their full, and effective, participation in society on an equal basis with others (WHO, 2011). Environment plays a huge role in the experience, and the extent, of the disability. It must also be noted that an impairment is a physical or mental state while disability is a social construction (Peek & Stough, 2010; Areheart, 2011). For example, lack of mobility is an impairment but an environment without ramps turns that impairment into a disability. Disability should not only be referred to as a health issue but rather encompass all other aspects like a person's biological, psychological, and social context.

According to the WHO (2011), disability includes a person born with inherited impairment such as cerebral palsy, a person who lost a leg due to an accident, and a person with dementia. Disability can be visible or invisible, and temporal, episodic, or long term (WHO, 2011). Disability is a worldwide phenomenon as people with disabilities are from all over the world and all have unique personal factors, differing in age, gender, socioeconomic status, sexuality, ethnicity, and cultural background (WHO, 2011). People with disabilities have rights just like other people and those rights are in place to protect, promote, and respect their inherent dignity and ensure the full, and equal, enjoyment of all human rights (WHO, 2011; African Child Policy Forum, 2011).

Morris (2001), on the other hand, defines the term *disability* as a disabling barrier of unequal access and negative attitudes. Morris argues that disability is prejudice and discriminates because it takes no account of people who have impairments and excludes them from mainstream activities. Morris further state that the word *disability* means disabling barriers enables people with disabilities to move away from the assumption that it is impairment which determines their life chances. If impairment determines people with disabilities experiences then the only things that they can be offered are treatments and cures, and services. Which prevent them from doing the kinds of things that non-disabled people do because they are not recognized as full human beings. It is this approach that leads to segregation, exclusion and ultimately to the assumption that their lives are not worth living (Morris, 2001)

3.3 Prevalence of Child Disability

There are 93 million children with moderate disabilities and 13 million children with severe disabilities worldwide (WHO, 2011). These children range between the ages of 0-14 years old (WHO, 2011). In South Africa, based on the 2011 census (Statistics South Africa, 2014), reports show that there are 10.8% of children living with a disability between the ages of 5-9 years. This is approximately 447.800 children. Furthermore, 4.1% of children with disabilities are between the ages of 10-14 years (approximately 161.800 children) and 2.6% of children with disabilities are between the ages of 15-19 years (approximately 108.700 children). However, the current statistics do not include children younger than 5 years as well as people with psychosocial and neurological disabilities because of limited data (SSA, 2014). The statistics are based on people with moderate to severe disabilities in seeing, hearing, communication, remembering/concentrating, walking and self-care.

3.4 Types of Disabilities in Children

There are different types of disabilities, ranging from psychological to physical disabilities. Psychological disabilities include learning disability, intellectual disability, mood disorder, autism spectrum disorder, oppositional defiant disorder, attention deficit hyperactivity disorder, conduct disorder and many other mental disorders prevalent to children. Psychological disabilities can be internalizing disorders while others can also be externalizing disorders. Internalizing disorders are disorders that occur within the child and they are not acted out externally in the environment like externalizing disorder (Austin, Bezuidenhout, Botha, Du Plessis, Du Plessis, Jordaan, Lake, Moletsane, Nel, Pillay, Ure, Visser, Von Krosigk & Vorster, 2015). Externalizing disorder are acted out by, and noticeable in, the child through their social interactions. An example of an externalizing disorder would be Attention-deficit/hyperactivity disorder. The following are examples of physical disabilities found in children — however it must be noted that physical disabilities are not limited to these only:

3.4.1 Down syndrome

Down syndrome is considered to be one of the leading major genetic causes of mental retardation (Zigman, 2013). Children with Down syndrome present with different degrees of cognitive disabilities, including comorbid behavioural traits and psychiatric disorders. Approximately 1 in 600 births are affected by trisomy of chromosome 21 (Davis, 2008). Common features of children with Down syndrome include facial characteristics of upward slanted palpebral fissures, epicanthal folds and rounded, and flattened, faces (Hwang & Jea, 2013).

Currently, the cause of Down syndrome is unclear and this makes it more difficult to manage it. A study conducted by Gilmore and Cuskelly (2012) states that the challenges of raising a child with Down syndrome do not significantly impact the maternal satisfaction and feelings of self-efficacy in a parenting role. These findings are quite surprising because one might assume that raising a child with Down syndrome would have a low maternal satisfaction considering the needs of a child with Down syndrome. However, Huiracocha, Almeida, Huiracocha, Arteaga, Arteaga and Blume (2017) state that the birth of a child with down syndrome places gender responsibility division in most households as it adds a greater burden to the mothers and this may then cause family dysfunction.

3.4.2 Cerebral palsy

Cerebral palsy is the most common cause of physical disability in children worldwide (Krigger, 2006). Celebral palsy describes a group of movement and posture developmental disorders. These disorders cause activity limitation and are attributed to non-progressive disturbances that occured in the developing foetal or infant brain (Bax, Goldstein, Rosenbaum, Leviton, Paneth, Dan & Damiano, 2005). It is assumed that cerebral palsy can result from an interaction of factors in prenatal, perinatal and postnatal stages of development (Krigger, 2006). It is classified according to three clinical presentations of motor deficits: spastic cerebral palsies, extrapyramidal cerebral palsies and hypotonic cerebral palsies (Fennel & Dike, 2001).

The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication perception, and/or by a seizure disorder (Dougherty, 2009). A study done by Tsibidaki (2020), suggest that families raising a child with cerebral palsy are able to cope with problems and conflicts that arise in their families. The study furthered shows the strength families have as he mentions that the findings do not mean that there are no challenges that parents encounter but rather that they have the ability, and willingness, to recognize and cope with them.

3.4.3 Spina bifida

Spina bifida refers to a neural tube malformation which results in speaking difficulties, and developmental defects of the spinal column in which the arches of one or more of the spinal vertebrae have failed to fuse together so that the spine is bifid (Dowrick & Dove, 1980). Children with spina bifida do not neccesarily have intellectual disability, however many children experience deficiencies on intellectual tasks (Burmeister, Hannay, Copeland, Fletcher, Boudousquie, & Dennis, 2005). According to Mitchell, Adzick, Melchionne, Pasquariello, Sutton and Whitehead (2004) spina bifida is caused by a variety of factors, including chromosome abnormalities, single gene disorders, and teratogenic exposure. They further mention that the cause is not known in many cases, but that it can be prevented up to 70% by maternal periconceptional folic acid supplements.

Many studies, including one done by Ong, Norshiree and Chandran (2011), show that parents raising children with spina bifida experience stress and report to have poor mental health (2011). They state that 40% of the mothers from their study reported to experience stress, while 23% reported poor mental health compared to parents who are not raising children with disabilities. They further state that parents' marital status had an effect as single parents were associated with parenting stress. This highlights the importance of having a partner/companion to moderate caregiving to the child. In the study, parents emphasized that having a strong marital relationship is more important than just the presence of the partner. Marital quality reflects parents’ satisfaction with the joint care for the child with disability.

3.4.4 Injury disabilities

Injury disabilities are either intentional injuries or unintentional injuries (Djeddah et al, 2000). According to Djeddah et al., (2000), intentional injuries are injuries that result from self-harm or interpersonal violence. In severe cases, intentional injuries may lead to injury-related deaths and can cause disability in both adults and children (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007). Unintentional injuries are a result of road-traffic injuries and other general incidents (Hyder et al, 2007). Road-traffic injuries are the sixth leading cause of death and the fourth leading cause of disability (Fuselli, 2012; Nantulya & Reich, 2003). The most common injury disability prevalent among children is Traumatic brain injury (TBI) (Hyder et al, 2007). TBI is defined at alteration of the brain functions due to external forces, resulting in brain pathology and neurological deficits (Braine & Smith, 2013). The external forces that cause TBI include falls, road accidents, assaults, abuse and sport related injuries.

3.5 Causes of Disability

Disabilities are caused by various factors. In developed countries, such as the United States of America, it is caused by chronic diseases such as mental illness, metabolic disorders, and cardiovascular diseases (Bauer, Briss, Goodman, & Bowman, 2014). It may also be caused by other factors including the consequences of alcohol and substance abuse (Bauer, Briss, Goodman, & Bowman, 2014). In developing countries, including South Africa, disability is caused by accidents, malnutrition, pre- and post-natal problems, violence, communicable diseases and congenital conditions (Graham, Selipsky, Moodley, Maina & Rowland, 2010; CPF, 2011). Due to poor nutrition, low education, lack of physical and financial access to healthcare and antennal services, people in rural areas of Africa are reported to have higher levels of people with disabilies than people in urban areas (ACPF, 2011).

Disabilities in children are common in both developed and developing countries (Mathye & Eksteen, 2016), but differ slightly on the contributing risk factors. Poverty, poor health, violence and malnutrition of pregnant and infants increases the risks of child disabilities in developing countries (ACPF, 2011). In South Africa, people have different beliefs and spiritual attribution regarding the contributing factors of disability. For example, some people associate disability with witchcraft or the will of God (Mathye & Eksteen, 2016). However, the causes of disabilities in both developed and developing countries can be divided into three factors: prenatal, perinatal and postnatal factors.

3.5.1 Prenatal Factors That Cause Disability

Disabilities are caused by many factors, one of which is genetic/chromosomal factors. Human beings are made up of different cells that have different functions for the whole body (Pevsner & Silverman, 2007). According to Pevsner and Silverman (2007), all cells within any individual's body have within them the same set of chromosomes — typically 46 in number. The chromosomes consist of long strings of DNA that are wound and arranged along their length into specific sequences corresponding to various genes (currently estimated to be 20,000 to 25,000 altogether) (Pevsner & Silverman, 2007). Each of these genes contain a code for manufacturing a specific protein needed for development and functioning, and these proteins are made as they are needed by the various cells and organs of our bodies (Pevsner & Silverman, 2007). This process is called gene expression (Pevsner & Silverman, 2007).

Pevsner and Silverman (2007) further explain that gene expression involves the synthesis of specific sequences of RNA that correspond to a respective protein. Therefore, DNA, RNA, and protein activity all play critical roles in human development and diversity. There are two main kinds of microarrays, which are a set of genes arranged for testing (Pevsner & Silverman, 2007). The first type is used to assess changes in chromosomal DNA in far more detail than was possible previously. Studies show that normal, healthy people could have substantial deletions or additions of selected portions of their DNA, suggesting that people can tolerate some imprecision in the mechanics of genetic regulation (Pevsner & Silverman, 2007). On the other hand, studies have also shown that these types of deletions and additions are more likely to be present among individuals with autism or intellectual disability which suggests that some DNA rearrangements have substantial impacts on development (Pevsner & Silverman, 2007). However, even now it is not evident that this can be seen to be the root cause of developmental impairments. In fact, there are dozens of known syndromes associated with developmental disability that involve either the loss or addition of small segments of DNA (Pevsner & Silverman, 2007).

Future research is needed to discover precisely which alterations in DNA can be well tolerated and which will have negative consequences on development, and why. As an example, one could consider the case of Down syndrome, the most prevalent genetic cause of intellectual disability (Pevsner & Silverman, 2007). Down syndrome is caused by the presence of an extra (third) copy of chromosome 21, but it has not discovered how the extra genetic material causes atypical development (Pevsner & Silverman, 2007). Mutations in a single gene, involving specific DNA alterations, have been shown to play a major role in causing at least some form of disorder (Pevsner & Silverman, 2007). Genetics play a role in many other disorders, including autism.

Beside genetics, other biological factors can cause disability. Antenatal birth defects are known to increase the chances for a child to have cerebral palsy (Pevsner & Silverman, 2007). Maternal diseases, such as respiratory, heart diseases, seizures and incompetent cervix, also present risks for children (Pevsner & Silverman, 2007). Maternal age over 40 years also poses risks for a child to have cerebral palsy and other disabilities (Pevsner & Silverman, 2007). Lastly, social factors can also have an influence in prenatal causes of disability. Fetal alcohol syndrome (FAS) is a birth defect caused by prenatal alcohol exposure where a mother of an unborn baby drank while pregnant. FAS refers to a constellation of physical, behavioural, and cognitive abnormalities. Children with FAS present with characteristics such as abnormal facial features, prenatal and postnatal growth abnormalities, and mental retardation (Riley, Infante & Warren, 2011). Approximately 80% of children with FAS show microcephaly (baby’s head being smaller than expected compared to other babies if the same age and sex) and behavioural abnormalities (Riley, Infante & Warren, 2011).

3.5.2 Perinatal Factors That Cause Disability

Perinatal is the phase of pregnancy that takes place between the 20th week and the moments immediately after birth (Schroth, 2010). Perinatal factors that because disability are not common, however, there are risk factors that might have an influence on this phase and might cause disability in children (Durkin, 2002). Issues like maternal nutrient deficiency and chronic illnesses, birth/pregnancy complications, infections, and premature births can cause disability in children (Abu-Saad & Fraser, 2010). Furthermore, neonatal meningitis — a serious medical condition in infants which is mostly the result of a blood bacterial infection — is a perinatal factor that causes disability in children (Abu-Saad & Fraser, 2010). A study done by Heath, Yusoff and Baker (2003) shows that meningitis in infancy has serious consequences that can result in death or a moderate to severe disability. Finally, maternal nutrient deficiency is mostly common in low and middle countries where mothers are often exposed to malnutrition and poor living conditions.

3.5.3 Post-natal Factors That Cause Disability in Children

Post-natal refers to the time after a baby is born (Cole, Williams & Wright, 2011). Post-natal factors that cause disability in this period are mostly due to accident/injury and, as discussed previously, traumatic brain injury is one of the primary causes of disability after a child is born (Elmore, 2019). This is followed by other accidents like falls, assaults, abuse and sport related injuries (Elmore, 2019). According to Johnson, Johnson, Heyhoe, Fielder and Dunning (2018), when a child is diagnosed with a disability during the post-natal period, parents do not get enough time to gather information about the disability or even be prepared to take care of their children with disabilities. In contrast, those whose diagnosis was identified before birth (by the use of an ultrasound scan during pregnancy) had some time to process the news and be emotionally prepared for the birth and the postnatal care of the child.

3.6 Parent's Reaction to Disability

Parents seek fulfilment in having children and watching them grow into responsible human beings, however, the joy of becoming a parent can be quickly diminished by the realization that the child has a lifelong illness or disability (Krstić, Mihić, & Mihić, 2015). Parents of children with disabilities react differently to the news that their children will live with disability and upon realizing that the new born child is severely disabled, or suffering from life-threatening conditions such as seizures or respiratory problems, parents can experience a strong feeling of powerlessness and an overwhelming uncertainty of what life would bring (Burton, Chen, Lethbridge & Phipps, 2017). Very often parents tend to have feelings of doubt, denial, the projection of blame, shame and guilt (Burton, Chen, Lethbridge & Phipps, 2017; Radzilani-Makatu, 2014; Davids, & de Jager, 2018; Krstić, Mihić, & Mihić, 2015).

Studies show that these feelings persist overtime as the child grows and fails to meet expected developmental milestones or as the child has periodic relapses of illness, repeated hospitalization, or medical demands (Coughlin & Sethares, 2017). During their study, Coughlin and Sethares (2017) indicated that there are gender differences in how parents react to their child's disability. Their study reported that mothers had more intense, or more significant experiences of, sorrow than fathers did. It revealed that mothers show feelings of emptiness, guilt, sadness, fear and depression while fathers show feelings of confusion and concerned about future problems and the stigma that is associated with disability. Furthermore, fathers show less depression when compared to mothers.

3.7 Phases of Reactions of Parents

In most cases, parents' initial reactions are likely to be negative but families either adapt flexibly, freeze in various degrees of rigid, ineffective reactions, or tend to resist, or even deny, the diagnosis itself (Davids, & de Jager, 2018). The parental satisfaction with the diagnostic process is related to the certainty of the diagnosis and the duration of the diagnostic process (Davids, & de Jager, 2018). It is also found that late diagnosis can cause the family/parents to not cope well, while early diagnosis can help the family/parents cope with a diagnosis better (Davids, & de Jager, 2018). According to a study conducted by Avieli and Band-Winterstein (2017) parents, react in three phases:

3.7.1 First Phase

The first phase is when parents are searching to find out what their child's diagnosis is. This can take months or even years (Avieli & Band-Winterstein, 2017). For most parents, the diagnosis of their child's disability is an initiation into a previously foreign world (Avieli & Band-Winterstein, 2017). Parents' realization that their future dreams and expectations have to change because of their new born child's disabilities is sometimes painful and the unexpected uncertainty about the future is exhausting for all parents realizing their child is disabled (Avieli & Band-Winterstein, 2017). The quest for a diagnosis mainly originates in the quest for 'knowing' — what the future might bring when the common dreams of normality were shattered. The feeling of powerlessness forces the parents to try to act, to try to do something, and to not just to sit and watch (Avieli & Band-Winterstein, 2017).

In a study conducted by Gundersen (2012), parents were mostly interested in finding information that would enable them to understand both the condition the child has and its potential impact on their life. Some conditions can be accurately diagnosed before birth, or shortly thereafter, due to evident genetic markers or obvious symptoms while other disorders may not present as obvious to either parents or medical professionals. For those who find out that something is wrong with their child before birth, the information comes as a shock (Gundersen, 2012).

Some disabilities become noticeable after birth and, most of the time, parents start to notice that the child is not reaching certain milestones and they start to have questions (Gundersen, 2012). From the moment they first worry that something might be less than perfect with their child, they must manage new, and often overwhelming, emotions. The search for a diagnosis involves procedures to test what is wrong with the child and this search can take months or even years (Avieli & Band- Winterstein, 2017). Parents' desperate search for a diagnosis is often triggered by the hope that if they received a diagnosis, they might be able to do something for their child (Avieli & Band-Winterstein, 2017).

Parents have different experiences regarding the search for diagnosis. Some are happy with all the procedures done — as long as they lead to a diagnosis — because getting a diagnosis brings psychological relief as they find it helpful to have a term to describe what is wrong with their child when asked by others (Avieli & Band- Winterstein, 2017). On the other hand, some parents find the experience traumatic because they feel that having a diagnosis is just having a name for the disorder and that it does not change anything. Furthermore, they feel that the diagnosis does not provide any useful information about the condition, or the future, and they rather seek to know what it means or what they can do to help their child.

3.7.2 Second Phase

According to Avieli and Band-Winterstein (2017), the phase when parents finally get to know the diagnosis is filled with emotions. Some parents perceive it as a 'turning point' (Avieli & Band-Winterstein, 2017). In this phase, 84% of parents, in a study conducted by Heiman (2002), state that they responded with negative emotions. They presented with feelings of guilt, depression, anger, shock, denial, fear, self-blame, sorrow, grief, confusion, despair, hostility and emotional breakdown (Heiman, 2002). 31% of parents presented with negative physiological responses like crying, not having appetite to eat, sweat, trembling, fear, physical pain (headache, stomach ache), and breakdown. However, other parents stated that they responded with positive emotions as they knew that something was wrong with their child but needed confirmation and information about what they can do (Heiman, 2002). Parents are introduced to new rules, barriers, requirements, decisions, and even a new language. Avieli and Band-Winterstein (2017) state that research in this phase has focused on developing guidelines on how health professions can effectively deliver the news to parents.

3.7.3 Last Phase

According to Avieli and Band-Winterstein (2017), the last phase is reconstructing normality. Parents try to normalize the child's life, taking into consideration all the challenges that come with disability. In the beginning, parents may face obstacles because they cannot easily access accurate information from professionals assisting with the diagnosis. However, after some time with the diagnosis, some parents find ways to cope with their child's disability (Avieli & Band-Winterstein, 2017). This includes the parents starting to accept the situation, getting on with life, and understanding and learning about the disability (Avieli & Band-Winterstein, 2017). Most parents compare their child's disability with other children and realize that they are far worse. Some look for information either online or from other parents to keep themselves informed about the disability (Avieli & Band-Winterstein, 2017).

3.8 Parenting Styles

Parenting refers to specific behaviours and methods (parenting practices) used by parents in raising children (Antonopoulou, Hadjikakou, Stampoltzis, & Nicolaou, 2012). These methods and behaviours are most likely to influence the child's psychological and behavioural well-being. Parenting practices are the behaviour parents use to communicate with their children and they include parental disciplinary strategies, how parents have discussions with their children, affectionate interactions, criticisms, and the provision of rewards (Antonopoulou et al., 2012), neglect (Kohl, Kagotho & Dixon, 2011).

According to Smetana (1995), there are three common parenting styles: authoritative, authoritarian and permissive. The fourth parenting style, neglectful parenting style, was incorporated into the list by Macobby and Martin (1983). These parenting styles reflect the patterns of parental values, practices, and behaviours as well as a distinct balance between responsiveness and demands (Roman, Makwakwa, & Lacante, 2016). Permissive parents are parents who are highly responsive and less demanding (Smetana, 1995), and these parents let their children do what they want to do without controlling them in any way. Disciplining the child is very rare in this kind of parenting style as parents are lenient, and avoid confronting the child.

In comparison, authoritative parents are parents who make rules that children are expected to follow (Baumrind, 2005). It is democratic based parenting, characterised by high demand and high responsiveness. Parents of this nature reason with the child but do not insist on obedience (Carter & Welch, 1981) and they nurture and forgive children. Based on a study conducted by Woolfson and Grant (2006), authoritative parents who are raising children with disabilities experience more stress than permissive parents. Perhaps it is because authoritative parents find it difficult to control their children due to factors related to the child's disability, and easy for perssimisive parents because of being reponsive and not demanding.

Also, authoritarian parents are parents who are characterised by high demand and less responsiveness. This type of parenting style values obedience and using forceful measures when the child does not follow what the parents want (Carter & Welch, 1981). Based on the Woolfson and Grant (2006) study, authoritarian parents also experience stress, especially when the child is a generally difficult child. In the study, they concluded that more parental stress is associated with control in the parenting styles.

The final parenting style is rejecting-neglecting parents. This type of parenting is characterised by few demands from the parent, less responsiveness, and little communication between the child and the parent. Parenting styles have an influence on parent-child relationships (Newman, Gozu, Guan, Lee, Li & Sasaki, 2015), and negative parenting can lead to maladaptive behaviours in children (Roman et al., 2016). As a result, this can have an impact on how the parents ensure the health and well-being of their children. Positive behaviours that parents engage in with their children with disability promote positive adjustment, emotional stability and psychosocial health (Antonopoulou et al., 2012).

3.9 The Parent-Child Relationship

The parent-child relationship is the quality of the emotional connection between child and parent (mother and/or father or significant parental figure) and the degree to which this connection is mutual and sustained over time (Lezin, Rolleri, Bean, & Taylor, 2004). The parent-child relationship is the foundation that shapes children’s development, well-being, adjustment, and how they become adults. This relationship is important because as it is an interacting platform for both parents and the child and parents provide for the child tangible and intangible resources for the child to reach his/her life goals (Akinnawo, Ocheho, Adegbayi, 2013).

The parent-child relationship of a parent and a child living with disability is different from parents caring for a typically developing child. Parents caring for children with a disability experience stress because of their child’s condition (Radzilani-Makatu, 2014) and this may affect how they raise their children. For instance, a study conducted by Baker, McIntyre, Blacher, Crnic, Edelbrock and Low (2003) where they compared parents raising children with developmental delays and parents raising children without development delays, showed that parents raising children with developmental delays experience more stress than the parents who raised children without any developmental delays. This means that parents raising children with disabilities may require special strategies to ensure the health and well-being of their children as well as a strong parent-child relationship.

According to Bae (2016), positively perceived parent-child relationships were related to fewer adolescent problem behaviours. If communication between the parent and child is lacking, parents have difficulties properly supervising their children, and, as a result, the likelihood of teenage problem behaviour becomes greater. However, when communication is constrained, conflict can arise in the parent-child relationship and, in turn, may lead to the adolescent evidencing higher rates of depression, delinquency, substance and alcohol abuse, sexual promiscuity, and lower school performance (Davidson & Cardemil, 2009).

3. 10 Health and wellbeing of children

Wellbeing is a dynamic state that is enhanced when people can fulfil their personal and social goals and achieve a sense of purpose in society (Statham & Chase, 2010). Rather than being static, wellbeing emerges from how people interact with the world around them at different points in their lives. It is not necessarily the same as being happy, since anxiety, depression and anger are sometimes to be expected in life (Statham & Chase, 2010). Well-being of children with disabilities mostly depends on their parents. As they are their primary caregivers.

Children’s wellbeing has also been described in many different and often inconsistent ways. An American study comparing wellbeing measures for children with and without limitations stated that children’s wellbeing was sometimes referred to as a ‘child’s environment’, an inherently positive state (happiness); the absence of wellbeing (depression); or in a collective manner (shared construct) (Foley, Blackmore, Girdler, O’Donnell, Glauert, Llewellyn &

Leonard, 2011). Children's wellbeing has also been described as varying according to life phase, age, gender, ethnicity, ability and disability and by contextual factors, including socio-economic status and geographical location (Foley et al, 2011). In order for children with disability to have good health and well-being, parents need to provide for them. Their provision includes the basic essential needs, and extra care that is needed by a person with disability, the medical care, time and other things.

3.11 Barriers and Facilitators in Ensuring Health and Well-being of Children with Disabilities

Parents can face significant challenges that can lead to personal distress and limit their capabilities which in turn can adversely affect the wellbeing of the child and the entire family unit. The following are the barriers that limit their capabilities to ensure the health and wellbeing of their children with disabilities:

3.11.1 Access to Information and Services

In a study conducted by Resch, Mireles, Benz, Grenwelge, Peterson and Zhang (2010), parents expressed how they often encountered many challenges when it came to accessing information and services that would help their children. Geographical distance is the major issues especially in low and middle income countries as health services are not easily accessible (Simpamba, Struthers & Mweshi, 2016; Walker, Alfonso, Colquitt, Weeks & Telfair, 2016; Zuurmond, Nyapera, Mwenda, Kisia, Rono & Palmer, 2016; Gundersen, 2012). Parents are required to walk long distances to get care for their children. In a study conducted by Coomer (2013), parents describe the lack of affordable transportation to access health services and mention that they do not have taxi fare for the transport. As they are from developing countries where employment is an issue, these parents struggle with taxi fare to and from the health care services. They claim that travelling on foot with a child with a mental disability is difficult and that travelling with a child with a physical disability is impossible.

Language is another barrier in accessing information and services (Zuurmond et al., 2016). Parents struggle to communicate with the health professionals and, in a study conducted by Coomer (2013), they indicated that sometimes the doctors do not want to use the language they understand even if they can speak the indigenous language. This can discourage parents from asking for clarification regarding the things they do not understand or even going to the health care services as they fear that they are not going to understand what the health professional says.

In a study conducted by Fellin, King, Esses, Lindsay and Klassen (2013), parents identify the health care system and doctors as authorities and state that they make it uncomfortable to ask all the questions they want to ask or to probe for more information regarding the health of their children. Health professionals do not share information about rehabilitation service options that can help parents (Zuurmond et al., 2016). The poor service that parents receive when visiting health services may act as a barrier in ensuring the health and well-being of their children with disabilities.

Parents also mention that health professionals are constantly changing in health services, which sometimes makes it hard for them as they have to keep restating what their children are suffering from (Coomer, 2013). They state that sometimes they get to the hospitals only to be told that doctors are not available so they should come on another day (Coomer, 2013), or that the health clinic/hospital has already taken enough patients for the day (Zuurmond et al., 2016). Lack of access to information and services, highlights how control over one’s environment is important in human capabilities. When parent do not have control over things like the language spoken to them when they are accessing services, their means of understanding their children with disabilities are decreased. Which will then go back to how effective they can ensure their health and well-being. Not being able to access services because of distance, parents might end up not going to health care facilities, and that can have an impact on the child's health.

3.11.2 Finances to Obtain Services

Resources, such as time and money, play an important role in the personal well-being of both the child and the parent (Burton, Lethbridge & Phip, 2018). Parents face financial challenges. In a study conducted by McNally and Mannan (2013) parents note the lack of money for both healthcare and necessities as the key challenges they face. Parents struggle to get help for their children because hospitals are expensive and most parents do not have medical aid to cover their children with disabilities (Resch et al., 2010). McNally and Mannan (2013) notes that these financial issues are as a result of lack of employment. Taking care of a child with disability limits the chance of parents going out to look for jobs, which puts them in a position of not having enough finances to do the things necessary for both themselves and their children with disabilities (Mitra et al., 2011).

3.11.3 Support

Support, whether from family, friends or health professionals, also plays a role in how parents ensure the health and well-being of their children. According to a study done by Resch et al. (2010), parents' well-being has an influence on the children's well-being. When parents do not get support when they need it, children are more likely to be at risk of not being well. According to Riany, Cuskelly and Meredit (2017), parents of a child with Autism Spectrum Disorder (ASD) in Indonesia indicated that they received less social support from family, friends and significant others because people in general think that having a child with disability is karma or a punishment to the parent for some past doings.

Furthermore, parents state that they do not get support from doctors (Coomer, 2013), saying that doctors just give them prescriptions and end consultations without any advice or support on how to deal with the disability. In a study conducted by Zuurmond et al. (2016), the stigmatisation of having a child with disability was the common reason why parents did not get support. Stigma is a complex phenomenon that discredits another person due to certain characteristics that a person might have (Link, & Phelan, 2001), it is often linked to the cultural context and disability. The stigma does not only limit parents from accessing support from family members and friends but also access to governmental support, NGO services and humanitarian programmes. Getting support from family members, friends, health professionals, and the community as a whole is important as it creates favourable social and environmental situations for parents and their families to engage in positive adjustment and initiatives that lead to positive outcomes (Zuurmond et al., 2016).

When parents receive support, they are able to become more resilient (Heiman, 2002) and be able to ensure the health and well-being of their children. Parents suggest that having a third person (social worker) in addition to themselves and doctors helps them access what they need to in order to take care of their children and use the services that are offered to them (Fellin, King, Esses, Lindsay & Klassen, 2013). In a study conducted by Heiman (2002), 95% of parents used different types of support including family members, friends, social workers, educational advisers, doctors, support groups, support from NGOs, and psychological and psychiatric consultations. Parents mention that knowing and networking with other parents who are also raising children with disabilities acts as a support because they are able to share information (Gardner & Harmon, 2002). With support, parents are able to maintain their routines and seeking support helps them to know how resilience is expressed, by doing something actual or practical about the situation.

3.11.4 Parents' Attitude Toward Disability

Parents' attitude plays a role in how parents ensure the health and well-being of their children with disability. The ability to frame, and reframe, events in positive terms is one way they are able to manage demanding situations (Gardner & Harmon, 2002). In a study conducted by McNally and Mannan (2013), most participants showed resilience and determination in taking care of their children with disabilities, and this had an influence on how they dealt with stigma. The study also reported that there were no instances where participants doubted themselves when they experienced stigma. In a study conducted by Heiman (2002), 75% of parents stated that their initial negative reaction towards their child's disability turned into feelings of joy, happiness, love and acceptance. With time, parents seem to adjust with their children and accept their children the way they and this, in turn, helps them deal with the challenges they encounter. A positive attitude towards life, with a willingness to accept and deal with the challenges they encounter, ensures their ability to take care of their children in a much better way (Gardner & Harmon, 2002). Finally, in a study by Heiman (2002), parents expressed a need for a strong belief in the child, and the child's future, the maintenance of an optimistic outlook at life, and a realistic view and acceptance of the situation helps.

3.11.5 Beliefs Parents Have Toward Children with Disabilities

Religious beliefs are another factor that most parents use to make sense of their children's disability. In most studies, parents attribute their children's disability to some higher power, saying that their children have a disability because it is God's decision, a curse, or the result of witchcraft (Mathye & Eksteen, 2016). The parents that believe their children have a disability because of witchcraft believe that there is someone who is responsible for the child's disability. In contrast, other parents use religious beliefs as a coping mechanism by believing that God gives them strength because it is His plan (McNally & Mannan, 2013). In a study done by Huiracocha-Tutiven et al. (2017) one parent states that children are their little angels sent by God regardless of disability while other parents believe that having a child with disability is seen as 'just bad luck' and a punishment (Gardner & Harmon, 2002), they do not relate it to witchcraft or even to any higher power.

3.12 Conclusion

In conclusion, the literature about children with disabilities looks mostly into the children, the experiences of the parents and how parents adjust to raising a child with disabilities. There are no studies that have focused on parents' capabilities of raising children with disabilities or on what parents actually do to ensure the health and well-being of their children. Therefore, this study is needed to add to the body of knowledge regarding parents' capabilities and in policy for the government to enhance parent's capabilities to ensure health and wellbeing of their children.

CHAPTER 4

METHODOLOGY

4.1 Introduction

This chapter presents the methodological processes of the study. It also outlines the aims and objectives of the study. The methodological processes include the research approach used when conducting the study, the research design used, and which data collection tools were used, as well as the process of data collections and the information regarding the population and sampling of the study. Finally, it covers the data analysis and all ethical considerations addressed during the study.

4.2 Research Aim and Objectives of the Study

The aim of the study refers to the broader statement that the researcher plans to do, or achieve (De Vos, Strydom, Fouche & Delport, 2011). It is a goal that the researcher wants to attain at the end of the study (De Vos, Strydom, Fouche & Delport, 2011). The aim of this study was to explore the strategies used by parents to ensure the health and well-being of their children living with a disability.

Thus, the objectives of this study were to:

1. Explore the parent-child relationship;
2. Explore the barriers and facilitators of health and well-being experienced by parents in caring for their children living with a disability;
3. Explore the strategies used by parents to ensure the health and well-being of their children living with a disability;

4. Explore how parents utilize their capabilities of (bodily health, emotions, affiliation and control of their environment) to ensure the health and well-being of their children with disabilities

4.3 Research Methodology

In this study, a qualitative research method was employed to explore the strategies used by parents to ensure the health and well-being of their children with disabilities. The purpose of a qualitative research study is to explore/describe phenomena that affect the lived reality of individuals, or groups, in a particular cultural and social context (Lichtman, 2014). Qualitative research is used to answer complex phenomena and has the purpose of understanding deep meanings (De Vos, Strydom, Fouche & Delport, 2011). It seeks to get an in-depth understanding of participants' views, opinions, experiences and perceptions (Shank, 2002).

Qualitative research produces descriptive data, which is exactly what participants said when being interviewed (De Vos et al., 2011). Neuman (2014) calls the actual words the participants said during interviews in the data collection process soft data. A qualitative research approach was chosen because it allows the researcher to be close to the participants to gain a better understanding of the strategies they use and capabilities they utilize to ensure the health and well-being of their children with disabilities. Also, a qualitative research approach allows flexibility in all aspects of its research process, thus making it more appropriate to explore a phenomenon (De Vos et al., 2011).

4.4 Characteristics of Qualitative Research

4.4.1 Natural setting: According to Creswell (2013), qualitative research studies phenomena in their own context, where participants have direct knowledge about what is being investigated. Information was gathered by directly talking to people and observing them within their own context. Participants were not taken out of their communities as the researcher went to their communities to collect data. This allowed participants to be comfortable, be in control, and to be able to fully express their reality and experiences. To ensure that the participants were not taken out of their natural setting, the researcher conducted the interviews in the participants' respective homes. When the interviews could not be conducted at a participants' home, the participants had a choice to choose a place where they preferred to be interviewed.

4.4.2 Researcher as Key Instrument: According to De Vos et al (2011), the researcher acts as the key instrument as they collect data themselves through the conduction of interviews, observations, or examination of documents. The researcher used an interview guide to collect data — as they get the information first hand — and the interview guide was developed by the researcher and not by someone else. In addition, the researcher physically went to the participant and initiated the conversation in a form of an interview to collect the data. The researcher also probed to get an in-depth description of participants' views and opinions regarding the strategies used by parents to ensure the health and well-being of their children with disabilities.

4.4.3 Inductive Reasoning/Data Analysis: According to Leedy and Ormrod (2005), qualitative research uses inductive reasoning, which is a pro cess that starts with observing a specific phenomenon from a sample and then drawing conclusions about the population from which the sample was taken in. It is different from quantitative research because quantitative research begins with assumptions which are tested to see whether they are true or not. Neuman (2014) says inductive reasoning is working from the "bottom up" process when the researcher moves from just a topic, and a few vague concepts, to developing an empirical generalization and identifying preliminary relationships by observing and refining data. In this study, a topic was identified from observing parents that are raising children with disabilities and who are facing many challenges. Collected data was based on a phenomenon that needed to be explored, which are the strategies used by parents raising children with disabilities to ensure health and well-being of their children even though they are facing different challenges. From the data collected, themes and sub-themes were created using thematic analysis. This was done through reading the data multiple times to get participant's meaning of what is being investigated, then made conclusions about the population.

4.4.4 Participant's Meanings: In qualitative research, the researcher must focus on the participant's opinions and experience regarding what is being investigated and not on what the literature says, or the meaning ascribed by the researcher (Creswell, 2013). The researcher in this study ensured that the meaning, experiences and opinions of the participants were presented the way participants voiced them. This was ensured in this study by using direct quotes from the transcription that were made from the data recorded during interviews in order to ensure that no information was lost or manipulated.

4.4.5 Theoretical Lens: Qualitative research often uses a lens when investigating a phenomena and this lens can be based on cultural, racial, or class differences or even other concepts (Creswell, 2013). This study used the capabilities approach lens to explore the strategies used by parents to ensure the health and well-being of their children with disabilities. Capability approach provides a tool, and a framework, that can be used for conceptualizing, evaluating, and assessing individuals' well-being and social arrangements (Alkire, 2008). Its primary role is to assess/evaluate phenomena which expanded human freedoms to a greater extent or the kinds of freedoms people have (Alkire, 2008). It was used in the study because it viewed disability and impairments as aspects of human diversity. It took into consideration the fact that humans are diverse, whether with or without disabilities, and thus it must be understood that they encompass different life situations and circumstances, which then required them to have different resources, freedoms and opportunities to convert them into desired and valued functionings. It advocates for equal distribution of resources to ensure equality in terms of justices (Alkire, 2008). The capability approach lens was used when the data was analysed to assess, and explore, capabilities that the parents have in ensuring the health and well-being of their children with disabilities.

4.5 Research Approach

This study used an exploratory research design. According to Neuman (2014), an exploratory research design expore a new area that has not been researched before, often using the “what” question. The researcher used an exploratory research design to explore the strategies used by parents to ensure the health and well-being of their children with disabilities. Exploratory is done to gain an understanding of a situation, phenomenon, community or individual; to discover new ideas, and to increase knowledge regarding a specific phenomenon (Neuman, 2014). Explorative research aims at applying new words, concepts, explanations, and theories to reality with the expectation of offering new ways of seeing and perceiving how other people’s reality really work, how they are organized, and in what way are they different from the usual. In other words, it offers an alternative way to "make sense" of the world, offering new approaches and angles, and alternatives to the act of explaining the world (Reiter, 2017).

This design is good for this study because there are no studies that look at the strategies used by parents to ensure the health and well-being of their children and there are no studies looking at them using a capability approach lens. Therefore, exploring this phenomenon will bring new knowledge. An exploratory design allows the study to be observed, and analysed, from a new, and different, angle. In the case of this study, an exploration, and analysis, into the strategies used by parents raising children with disability in their natural setting unveil realities which were hidden. Capability approach provides a tool and a framework which can be used for conceptualizing, evaluating and assessing individuals’ well-being and social arrangements (Alkire, 2008). Its primary role is to assess/evaluate the kinds of freedoms people have and the phenomena which expand human freedoms to a greater extent (Alkire, 2008). It takes into consideration that humans are diverse, whether with or without disabilities and that they need to be understood as encompassing different life situations and circumstances, which then requires them to have different resources, freedoms and opportunities to convert them into desired and valued functionings.

The aim of using exploratory design and capability approach is to extend, expand and diversify tools and frameworks with the expectation that we explore more and make sense of what was previously not taken into consideration (Reiter, 2017). In this study, exploratory design was used during the formation of the interview guide in developing questions that aimed at getting an in-depth opinions and views of the participants, as well as during the interview with probing to get more information from the participants.

4.6 Research Setting

The interviews were conducted in different homes where participants resided within the city of Cape Town's townships. The city of Cape Town is the metropolitan municipality in the Western Cape Province with a total population of 3.740.025. The population is made up of the following groups: Coloured 42,4%, black African 38,6%, white 15,7%, Indian/Asian 1,4% and other 1,9% (SSA, 2014). Some of the well-known townships in the city of Cape Town include Khayelitsha, Heideveld, Gugulethu, Langa, Hanover Park, Nyanga and Manenberg, they are located in the cape flats which is a home to most coloured and blacks. Up to 36% of the households live below the poverty line and there is an unemployment rate of up to 23,9%. The contacts for the recruitment of this study were found in organisations such as churches, ECD centres and NGOs within the townships and schools that specialize in special education for disabled children.

4.7 Population

According to Boslaugh (2008), the population consists of people, objects, or events, which a researcher would like to draw conclusions on, population is the set of all the members of the group that present the same characteristics. Population is a group of people with specific characteristics whom the results are intended to generalize (Terre Blanche, Durrheim & Painter, 2006). For example, if the researcher wants to do an investigation on parents in South Africa, the population then becomes every parent in South Africa. It is a larger pool where samples will be extracted from. The population possesses all the inclusion and exclusion criteria of the study so that a sample can be selected to represent the whole population (Blanche et al., 2006). The population of this study were parents raising children with any disabilities. The population included both mothers and fathers who had children with disability, under the age of 18 years. The parents that participated in this study were mostly residing in the city of Cape Town cape flat, Bishop Lavis, Delft, Gugulethu, Uitsig, Mfuleni and Durbanville. The researcher targeted parents from diverse areas of Cape Town as access to more affluent areas was limited.

4.8 Sampling

Daniel (2012) defines sampling as the selection of a few cases, people, objects, or events from a larger population for inclusion in a study. Because a researcher cannot conduct a study on the entire population, they must use a representative sample, or a small collection of units from a much larger population, to study the smaller group and to produce accurate generalizations about the larger group (Neuman, 2014). There are two different sampling techniques — random and non-random sampling. This study used a non-random sampling because it is a qualitative study that aimed to get descriptive data regarding the views and opinions of a phenomena that is not generally known by just any parent but specifically parents that are raising children with disabilities.

Under non-random sampling there are different techniques and they include purposive, snowball, convenience, and haphazard sampling. They are all different and a researcher chooses one that best fits the study based on two motivations — time and cost. Researchers must look at both the time and cost of finding the participants and the accuracy that the chosen sample will bring to the study (Neuman, 2014). This study used purposive sampling strategy/technique to select participants. Purposive sampling is a non-random sampling technique in which the researcher selects participants based on their knowledge and relation to the study (Neuman, 2014; Daniel, 2012). The researcher selected parents raising children with disabilities in the city of Cape Town because they serve the aim of the study with their experience and knowledge of raising a child with disability.

Furthermore, the researcher purposively selected 12 parents that are taking care of children with any disabilities, recruiting them in local organisations and schools. The participants were selected based on their interest in the study and free will to participate. The researcher made contact with gatekeepers from the organisations and schools in order to have access to the parents. The parents were then told about the study and asked if they were willing to participate by the gatekeeper. After agreeing with the gatekeeper, the researcher then made contact with the parents directly to further explain the study before setting up a meeting to conduct the interviews.

4.9 Data collection tools

An interview schedule was used as a guide while doing the interviews. An interview schedule is a schematic presentation of the core questions that need to be investigated by the interviewer to answer research questions (Curtis & Curtis, 2011). Interview schedules contain semi-structured questions that have an introduction/opening question, core in-depth questions and closure (Blandford, 2013). It is important for a researcher to have prepared questions written down; however, the interviewer is not forced to strictly stick to the questions verbatim when interviewing participants. Rather, they are just a guide and reminder for the interviewer. Introductions include thanking the participant for agreeing to participate in the study and explaining the participant's rights during the interview. Opening questions include demographics of the participants and their child with a disability. In addition, the following questions will also be asked:

- What kind of disability does the child have?
- How long has the child been diagnosed?

The core, in-depth questions included for the study include the following questions which speaks more on the objectives of the study:

- What is the nature of the relationship between the parent and child with disability?
- On a daily basis, what do you do as a parent to make sure that your child is healthy and well taken care of?
- How do you express your emotions?
- Are there any services available in your community to help parents/caregivers of children with disabilities?

Lastly, closure questions included asking the parents about what they think the government should offer to parents raising children with disabilities to enhance their capabilities and ensure the health and well-being of their children (see APPENDIX A).

An audio-recorder was used to effectively capture data when conducting an interview and the participants gave their consent to be recorded.

4.10 Qualitative Research Method Used in the Study

The term *methods* refer to the ways in which qualitative researchers collect data to build their investigation (Given, 2008). Qualitative research has different methods that can be utilized by qualitative researchers to gather the information they seek to answer their research questions. These include interviews, participant observations and the collection of documentary materials. Participant observation uses the researcher as a tool for collecting data and requires the researcher to be fully immersed in the social reality of the participants (Corbetta, 2003). Documentary material is any written, printed, photographed, painted information that can be used to provide information and answer research questions (Tight, 2019). In this study, interviews were chosen as the data collection method.

4.10.1 Interviews

This study used interviews to explore the strategies used by parents to ensure the health and well-being of their children with disabilities. Interviews are a conversation between an interviewer (asking questions and listening) and an interviewee (answering questions) (Warren, 2001). The interviewer co-ordinates the conversation and aims to get the participants' in-depth opinions and experiences. Unlike a survey, the epistemology of the qualitative interviews is more constructionist than positivist and are based on the participants' opinions and views rather than science (Warren, 2001).

In interviews, participants are viewed as meaning makers and not just passive beings who choose answers from existing choices that they are provided with. In this study, participants — which in this case are the interviewees — were identified based on their knowledge/experience about the issue being investigated. The interviewer initiated contact with the participant after getting permission from the Higher Degrees Ethics Committee of the University of the Western Cape and a go-ahead from the gatekeepers. The interviewer then scheduled meetings to conduct the interview in settings that the participants were comfortable with. Ground rules and consent were set out before the interview began (Gubrium & Holstein, 2001).

There are different types of interviews and qualitative researchers need to know which one will produce the most useful information to answer their research questions (Gubrium & Holstein, 2001). There are face-to-face interviews, telephone interviews and focus groups. Focus group interviews are a research technique that collects data through group interacting on a topic determined by the researcher, basically having more than one participant during an interview and interacting on the same conversation (Morgan, 2001). Telephone interviews are the use of a telephone to connect with the participant and the hosting of a conversation over the telephone. This study used face-to-face interviews, using a semi-structured interview guide. Face-to-face interviews are the most flexible method of collecting data as they allow the researcher to both structure the interview and motivate the participant (Taylor, 2005). In addition, they also allow better communication between the two parties involved as both verbal and non-verbal communication are easily observed (Leeuw, 2008).

4.11 Data Collection Process

After getting permission from the Higher Degrees Ethics Committee of the University of the Western Cape, the researcher made contact with gatekeepers in both the organizations and schools to access parents (which were two principals for the schools and a social worker in an NGO). The researcher explained the study, the aim of the study, the importance of conducting the study and the study can help parents, government and policy makers, to the gatekeepers. The gatekeepers the made contact with the parents for the researcher. After the parents agreed to be part of the study with the gatekeeper, the gatekeeper then contacted the researcher to set meetings with the parents in preparation for the interview. The researcher contacted the parents and explained the study before agreeing on the interview meeting. During that contact, an agreement was made regarding when the interview would take place. The researcher then conducted the interviews at the participants' preferred places. For most of the parents, the interviews took place at their homes, but for some parents the interviews took place in a school where parents were working.

Before the interviews started, the researcher explained the study to the participants, in language they understood. The researcher also explained the information sheet which had the rights of the participants and information about the research. The researcher then gave the participants a consent form to sign when they agreed to participate in the study. The interviews took place in settings where the participants were in private spaces that were preferred by them.

With participants' agreement to participate, data was then collected using face-to-face interviews using the interview schedule to ask the participants questions (Neuman, 2014). The interview schedule was used to guide the researcher to ask key questions that would answer the research questions, to have an in-depth understanding of parenting realities while also allowing parents to express themselves free (Bradshaw, Atkinson, & Doody, 2017). 12 individual interviews were conducted until data saturation was reached. Data saturation is when there is no new information obtained from the interviews (Fusch & Ness, 2015). All ethical considerations were explained to the participants before the interviews took place and the participants were requested to complete a consent form before participating in the study. Permission to use an audio voice recorder was requested from the participants before the interview. As one participant did not want to be recorded, the researcher took notes of their specific interview.

4.12 Data Analysis

Data collected was analysed using thematic analysis. The digital audio recordings were transcribed verbatim and the transcripts were analysed using thematic analysis. Thematic analysis is a method of identifying, analysing and reporting themes within the data (Clarke & Braun, 2014). According to Nishishiba, Jones and Kraner (2014), thematic analysis focuses on identifying themes that adequately represent the data. Themes are key patterns identified in the data that may — according to the purposes of the research question — be important features of the phenomenon in question. A researcher identifies themes by going through multiple examinations of the data and reading through the data repeatedly. This analytical approach organizes data and describes it in full detail. According to Clarke and Braun (2014), thematic analysis is conducted in six phases:

- **Familiarizing yourself with the data:** In the first phase, the researcher should immerse herself/himself with the data by reading and rereading textual data and also listening to audio-recorded data and transcribing verbatim to produce transcripts (textual data). In this study, the researcher listened to the recorded audios twice, then transcribed the interviews verbatim. After transcribing, the researcher read and reread the transcriptions multiple times to be familiar with what the respondents were saying. The aim of this phase was to become intimately familiar with the data and to be able to notice, and learn, things that were relevant to the research questions.
- **Generating initial codes:** The second phase is the start of the systematic analysis of data through coding as codes are the building blocks of analysis. When generating codes, the researcher looked for specific issues of importance that were common to the respondents and information that was used to answer the research questions.
- **Searching for themes:** In this phase, the researcher grouped the codes according to how related they were to form themes. Themes consist of the important content of the data in relation to the research question. Searching for themes is an active process and the researcher constructs the themes, rather than discovering them, despite what this

phase is called. In this study, the researcher collapsed codes that showed similar ideas together to form themes.

- **Refining and reviewing the themes:** In the fourth phase, the researcher reviewed and refined themes with the codes in order to discover whether they were related or not.
- **Defining and naming the themes:** In this phase of data analysis, the researcher named and defined themes as well as identified the importance of each theme and determined what aspects of the data each theme captures.
- **Producing reports:** This is the last phase. The researcher produced a full thematic analysis report in the form of results, which is found in Chapter 5. This chapter of the study is the report of the analysis and includes all the themes that emerged from the data.

Thematic Analysis offers a toolkit for researchers who want to do robust, and even sophisticated, analyses of qualitative data while simultaneously focusing on, and presenting, the data in a way that is readily accessible to those who are not part of academic communities (Clarke & Braun, 2014). It is easy to learn from data analysed using thematic analysis and it works well for people who are less familiar with qualitative studies.

4.13 Trustworthiness

Cope (2014) states that qualitative research was once seen as “soft” science, noting that it lacks scientific rigour compared to quantitative research. It is sometimes said that qualitative research is subjective, prone to researchers’ bias, and lacks generalizability. Trustworthiness is defined as the quality of an investigation (and its findings) that make it significant to audiences (Cope, 2014). In this study, trustworthiness was ensured by applying the following principles:

4.13.1 Credibility

According to Cope (2014), credibility refers to the truth of the data, or participants' views, and the interpretation and representation of them by the researcher. It is the researcher's responsibility to make sure that the study is accurate and constant**.** The researcher enhances credibility by describing his or her experiences as a researcher and verifying the research findings with the participants (Cope, 2014). In this study, credibility was maintained by using an accurate reflection of the information provided by the participants and by using the exact quotes from the recording (Cho & Trent, 2006). Furthermore, authenticity was ensured by using open-ended questions and answers that afforded the participant the opportunity to authentically express him or herself (Blanche & Durrheim, 2004).

4.13.2 Conformability

Cope (2014) states that conformability refers to the researcher's ability to demonstrate that the results of the study represent the participants' responses and are not the researcher's biases or viewpoints. Conformability is the concept that someone other than the researcher can confirm the data. Conformability can be demonstrated by describing how data was analysed and showing that the results are taken directly taken from the data. The researcher shows this by presenting direct quotes from the data for each theme that emerged (Cope, 2014). In this study, conformability was maintained by ensuring objectivity through the derivation of findings from the data and not from any researcher's bias (Korstjens & Moser, 2018).

4.13.3 Transferability

Transferability is the ability to generalize the findings of the study onto a larger population (Krefting, 1991). Cope (2014) states that transferability refers to findings that can be applied to other settings or groups. In order for a study to meet the transferability criteria, the reader must find meaning in the results of the study and be able to apply them to their own similar experiences. To make a study transferable, a researcher needs to provide enough information about the participants, and the context of the study, to allow the reader to be able to assess the findings to see if the study is transferable or not (Cope, 2014). However, the study and the experience being compared to the study should be similar to each other. In this study, transferability was maintained by making sure that the findings fit into contexts outside the study (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014). Information about the context of the population is provided in research setting above and information about participants is provided in the demographics section in the next chapter.

4.13.4 Dependability

Dependability refers to the stability of data over time and under different conditions (Cope, 2014). Dependability is achieved when another researcher uses the same procedure and steps to conduct research of the same kind, with similar participants, under the same conditions and get the same results. Dependability was maintained by using an appropriate criterion for selecting participants, (Elo et al., 2014), which, in this study, was purposive sampling. The researcher also mentioned the participants' demographics and data collection procedure/process.

4.13.5 Triangulation

Triangulation is the use of multiple methods and a plan of action that that helps to avoid researcher's bias that may stem from using a single method (Cope, 2014). Triangulation can be in the form of using different methods and researchers (Babbie & Mouton, 2001). Triangulation is considered the best way to enhance validity and reliability in a study. Triangulation was used to validate commonalities that arose in the interviews by having a second observer during data analysis. The researcher's supervisor was the second observer. Triangulation of the observer decreases the potential of bias in gathering, reporting, coding, or analysing of the data (Thurmond, 2001).

4.14 Reflexivity

Reflexivity refers to the "continuous process of self-reflection that researchers engage in to generate awareness about their actions, feelings and perceptions" (Darawsheh, 2014). Lambert, Jomeen, and McSherry (2010) define it as a process whereby the researcher continuously reflects on their actions, values and perceptions and note how they can have an impact upon the research and affect data collection and analysis. Reflexivity is a strategy that researchers can use to understand the phenomenon that is being investigated and accurately portray the meaning made by participants, especially where self-reflection allows assumptions and biases that could affect the understanding of the study. It is therefore important that a researcher pay attention to personal factors (actions, perceptions, values and feelings) that might influence and affect the outcomes of the research in a negative or positive way. Researchers can do this by maintaining a reflexive journal to reflect and note thoughts, and feelings, in an effort to bracket perceptions and subjectivity (Cope, 2014). Finally, the researcher controlled biases during the whole study, especially when collecting, analysing, and interpreting data.

4.15 Conclusion

This chapter consisted of the methodological design of this current study. A qualitative design was selected in order to provide an in-depth exploration into the strategies used by parents to ensure the health and well-being of their children with disabilities, using the capability approach lens. This chapter provided information regarding the various stages of the research process, such as data collection process and tools, data analysis, and trustworthiness as well as a detailed account of population and the method of sampling. The chapters to follow will provide the results, discussions, and conclusion of this research.

CHAPTER 5

RESULTS AND DISCUSSION

5.1 Introduction

The purpose of this study was to explore and describe the strategies parents use to ensure the health and well-being of their children with disabilities. In order for the study to reach its aims, qualitative methodological approaches were employed to collect data using face-to-face interviews. The data was analysed using thematic analysis. This provided an indication of the context of the conversations between participants and the interviewer and looked at the meaning attached to the information collected from the participants. The human capabilities approach is used as a methodological and theoretical framework to explore the findings.

5.2 The Human Capabilities Lens

The capability approach is not a theory that can be used to explain poverty, inequality and well-being, however, the approach provides a tool and a framework which can be used for conceptualizing, evaluating and assessing individuals' well-being and social arrangements (Alkire, 2008). The primary role of the capability approach is to assess/evaluate the kinds of freedoms people have and the phenomena which expand human freedoms to a greater extent (Alkire, 2008). Capability approach is open to many different forms of specifications regarding what constitutes valuable capabilities to achieve desired functionings, because they depend on what a person regards as valuable. What is valuable to one person might be different to the other person.

The 10 central human capabilities presented by Nussbaum (2007, 2011) aim to help in identifying, and clarifying, a set of capabilities. Furthermore, they highlight important capabilities that might be overlooked or not addressed at all. This approach is a normative proposition, looking at social arrangements that should be primarily evaluated according to the extent of freedom that people have to promote or achieve functionings they value (Alkire, 2008). The important insight provided by CA regarding disability is that it views disability and impairments as aspects of human diversity. It encourages the understanding that humans are diverse, whether with or without disabilities, and, therefore, it must be understood that they encompass different life situations and circumstances which require them to have different resources, freedoms and opportunities to convert into desired and valued functionings. Meaning there is an overlap between a disability and an individual's life or social arragements to convert opportunities to functionings.

Parents raising children with disabilities face many challenges which hinder their ability to perform certain functionings that other parents raising typical developing children are performing. But with human capability lens, parents should be looked at based on their capabilities, to be able to see their specific needs, which they would then highlight which opportunities would be suitable for them achieve functionings that are valued by them. Another perspective provided by CA highlights the importance of human diversity in the evaluation of people's relative advantages or disadvantages (Alkire, 2008). This entails the evaluation of disability in relation to how resources/freedom and opportunities are distributed to ensure equality in terms of justice. Looking at disability through the lens of CA allows overcoming the duality between individual and social models of disability but to see disability as inherently relational.

According to Hartas (2014), functionings are what people achieve and capabilities are the abilities to achieve those functionings. He states that when it comes to children's well-being, a parent's functionings refers to parental behaviour and practices that support children and ensure they live a life they value while simultaneously acknowledging the existence of social and structural constraints. On the other hand, capability refers to a parent's ability to operate within these constraints and convert the real opportunities they are afforded into valued functionings, therefore, ultimately exercising the freedom to choose among possible lifestyles (Hartas, 2014). This study explores the parental behaviours (strategies) and practices in order to see how parents ensure the health and wellbeing of their children with disabilities. The study uses the capability approach to assess/evaluate whether their capabilities are enough or whether they need extra support in terms of freedom and opportunities to strengthen their capabilities in order to achieve valued functioning.

The capability approach can be used in different ways to evaluate, assess and compare phenomena. Babic, Graf and Germes Castro (2010) conducted a study on child and youth care where they first let people define what they considered to be fundamental in their respective context, and then what they valued, in order to understand their capabilities and intended functionings. That was done in order to be able to gain participants adequate notion of valued functionings and capabilities based on their needs, to be able provide reliable criteria to assess and optimise their work to be able to support the development of new programmes and services. In Babic et al, (2010) study, capabilities were not pre-defined like the capabilities presented by Nussbaum, as the central capabilities to look at. However, in this study, the researcher used four of the Nussbaum 10 central human capabilities to analyse the results of this study and to assess parents using the four capabilities Nussbaum presented as important on those capabilities to achieve a valuable life worthy of living.

5.3 Demographics of the Participants

Table 1 Demographics Data of the Participants

PARTICIPANT NUMBER	LANGUAGE	AGE	GENDER	AGE OF THE CHILD	GENDER OF THE CHILD	RACE	NUMBER OF CHILDREN	GRANT	TYPE OF DISABILITY	EMPLOYMENT STATUS
1	Xhosa	60	Female	14	Female	Black	4	No grant	Physical disability	Volunteering
2	Xhosa	43	Female	24	Female	Black	4	Disability grant	Physical disability	Contract
3	Xhosa	37	Female	7	Male	Black	3	Disability grant	Physical disability	Not employed
4	Xhosa	40	Female	6	Female	Black	4	Disability grant	Physical disability	Not employed
5	Afrikaans	40	Female	9/11	Female/Male	Coloured	5	Disability grant	Physical disability	Not employed
6	Xhosa	35	Female	13	Male	Black	1	Disability	Physical disability	Not employed
7	Xhosa	50	Female	20	Female	Black	4	Disability grant	Physical disability	Employed
8	Afrikaans	53	Female	14	Male	Coloured	3	Disability grant	Physical disability	Not employed
9	English	29	Female	14	Female	Coloured	3	Disability grant.	Physical disability	Part-time
10	Afrikaans	49	Female	14	Female	Coloured	4	Care dependency	Physical disability	Not employed
11	Afrikaans	60	Male	12	Female	Coloured	3	Disability grant	Physical disability	Employed
12	Afrikaans	47	Female	12	Male	White	3	No grant	Physical disability	Employed

5.3.1 Summary of Demographics

Table 5.1 tabulates the characteristics of the participants that participated in this study. The table includes the participants' language, age, gender, the ages of their children with disability, their child gender, their race, total number of children they have, grant they receive, and their employment status. The sample consists of n= 12 participants, ranging from the ages of 29 years old to 60 years old. This highlights that parents can have a child with disability irrespective of their age, socio-economic status, or level of education (Resch, et al, 2010; Gona, Mugala, Odera, Newton & Hartley, 2010). Most parents in this study were female participants and mothers to the children with disabilities. There was one male participant who was interviewed as caregiver as he is the grandfather of a child with disability.

It should be noted that having mostly mothers as participants in a study about children with disability is very common. In a study conducted by Rugoho and Maphosa (2016), only five fathers were involved compared to the nine female participants. This shows that, because of the functions inherent to being a mother, housewife and permanent caregiver, mothers bear the most burden when it comes to taking care of their children and that is not the same with fathers who are mostly seen as the breadwinners who work most of the time (Tigere & Makhubele, 2019; Cohen, 2010).

Participants were mostly isiXhosa and Afrikaans speaking, and only two participants spoke English. These languages are the languages that are commonly spoken in the city of Cape Town, with Afrikaans being the most common language spoken by 34.9% of the population, English being spoken by 27.8% of people and IsiXhosa being used by 29.2% of the population (SSA). Based on the table above, most parents were parents to more than one child and, in most cases, the child with the disability was either the first-born or the last-born child. However, there was one participant with only one child — the one with a disability.

Moreover, one parent had five children in total with two of their children having disabilities. The majority of the parents had female children who presented with disability and only four parents had male children with disabilities. Participants in this study were Blacks (50%) and

Coloured (42%). ‘Coloured’ is a race group of mixed descent in South Africa (de Wit, Delport, Rugamika, Meintjes, Möller, van Helden, Seoighe & Hoal, 2012). There was one White participant. According to the provincial racial demographics, Coloured people consist of 42.4% of the Western Cape population, followed by Blacks with 38.6% and 15.7% of white people (SSA).

In this study, 83.4% participants reported that they receive a disability grant, which is about R1700 a month from the government. One participant mentioned that she gets a care dependency grant and two participants reported that they do not get grants from the government. In South Africa, 45.2% of households nationwide depend on government grants, whether the grant is a child grant, old age grant, or a disability grant. In the Western Cape Province, 37.3% households receive grants as their source of income, with 10.3% of those households having grants as their only source of income. In this study, 50% of the participants mentioned that the grant they receive is their main source of income. This means that they are dependent on the grant money for food and necessities for both their child with a disability and their entire family.

Most participants in this study were unemployed as only three participants reported that they were employed permanently. One participant reported to be working part-time while another stated that she was volunteering and a third noted they were under a contact. Fifty percent (50%) of participants were not employed at all, making the disability grant the only source of income received by those participants. These results are consistent with the participants in a study that was done by Rugoho and Maphosa (2016) as 50% of the participants in their study were also unemployed and their ability to support themselves depended on grants.

When considering the unemployment rate for this study, it is important to note that the participants survive on, and support their families with, the R1700 they receive from the government. This highlights the challenges that parents raising children with disabilities experience. The parenting responsibilities of a parent raising a child with a disability require time, finances, and are physically and emotionally demanding (Resch et al., 2010). Furthermore, they can affect social relationships and caregivers' employment. Dependence on the disability grant, and the inability to work due to different reasons, means that the parents do not have enough freedom and opportunities. This influences the parents' ability to ensure their children's well-being and health because they do not have enough money to meet all necessities.

5.4 Thematic Findings of the Study

The data consisted of 12 interviews that were conducted using a semi structured interview guide. The interviews were audio-recorded and transcribed verbatim. They were then analysed using thematic analysis, following Braum and Clark's (2014) stages of thematic analysis. The results are described and presented in themes and sub-themes that emerged from the data codes. The results are presented, and discussed, with the support of direct quotes from the transcribed data and references made to relevant literature and theory in order to validate the study.

Table 2 Themes and Sub-Themes

The table below presents the pre-determined themes and its sub-themes, as well as additional themes that emerged and their sub-themes:

Pre-determined themes	Sub-themes
5.5. Capabilities of emotions	5.5.1. Expression of Emotions 5.5.2. Dealing with Emotions 5.5.3. How parents are accepting love and support

5.6. Capabilities of affiliation	5.6.1 Relationship and friendships on parents raising children with disabilities 5.6.2 The respect parents get from society
5.7. Capabilities of control over one's environment	
5.8 Capabilities of bodily health	
Additional themes	**Sub-themes**
5.9. The kind of relationship parents have with their children with disabilities.	
5.10 Strategies and facilitators used to ensure health and well-being	5.10.1 Encouragement 5.10.2 Availability 5.10.3 Support
5.11. Barriers that prevent parents to ensure health and well-being	5.11.1 Finances

Pre-determined Themes

5.5 Theme 1: Capabilities of Emotions

Parents in this study were asked about their emotions to gain more understanding about their emotional capabilities to ensure the health and well-being of their children with disabilities. The sub-themes that emerged from this theme are: expression of emotions, dealing with emotions, and accepting love and support.

5.5.1 Sub-Theme: Expression of Emotions

Emotions increase an individual's survival and help individuals to address, or overcome, problems that they might be facing (Fischer & Manstead, 2008). Parents raising children with disabilities encounter different emotions that are triggered by different situations they find themselves in. Those situations include not getting support, marital issues, adjusting to their new lives and many other challenges they experience. They find themselves having to deal with anger, sadness, love, joy and other emotions, and they deal with them differently. According to Plumb (2014), emotions are an important contributor to the way people think, and learn, about life, personal vulnerability, dependency on others, and how people can support each other to flourish.

Emotions are important in relationships with ourselves and others because of the communicative function they serve. Hurt feelings are a sign that there is a need for reconciliation, while anger can convey that these are undesirable behaviour that must change, and sadness and anxiety often elicits care and support (Overall, Clark, Fletcher, Peters & Chang, 2020). Parents' beliefs about emotions, and how they express their emotions, has an impact on how children create their own self and world schemas about emotions (Dunsmore, Her, Halberstadt & Perez-Rivera, 2009). Thus, parents' way of expressing their emotions is important because they have an influence over their children's emotion regulation, emotion knowledge and socio-emotional development. From an early age, parents' expression of emotions has an influence on a parent-child relationship, and they are particularly important at that stage as a child is solely dependent on non-verbal and emotional interactions with their parents (Schultheis, Mayes & Rutherford, 2019).

> *"I speak to that person, and tell the person that this and that I don't like it..."* P6

The above quote shows that the participant does express her emotions. Expression of emotions is considered to be helpful in dealing with emotions (van Leeuwen, Bossema, van Middendorp, Kruize, Bootsma, Bijlsma & Geenen, 2012). It is one of the three emotion regulation strategies that people use to control their emotions. Expression of emotions means the sharing of inner feelings, both interpersonal and intrapersonal feelings (van Leeuwen et al, 2012). In this study, most parents reported that they express their emotions verbally for the other person to know that something has made them feel a certain way, whether that be in a good or bad way. Another participant reported to do something similar to the previous one, saying:

> *"when these something I don't like, and say 'ay no there I don't like it, you were not supposed to have put it like that, you suppose to put it like this'"* P4

However, unlike the above parents, somes parents struggled to express their emotions and preferred to keep things to themselves or to communicate them non-verbally. One parent mentioned that she finds it hard to express her emotions and so she prefers to keep quiet. She said that when she is like that, her children already know they should not come close to her. She mentions that sometimes she will speak to her husband but she believes that he does not understand her because he is a male. She will then go to someone who will understand her from a woman's perspective.

> *"Yes I will speak to my husband, but sometimes he doesn't understand because he is a guy and he is not a woman…"* P9

The quote above shows the differences in gender in terms of emotion expression as males are known to "keep in" their emotions and not express them (Chaplin, 2015). As a result, the quote shows that males show less empathy and sympathy than females and the participant feels that her husband sometimes does not understand her when she expresses her emotions because he is a man. This highlights that sometimes a person can have the emotional capabilities but if the environment the person is in does not accommodate those capabilities the person will not achieve desired functionings. Having a partner that listens and being understood and supported when in need of the support. It also highlights a parent-child relationship that the parent has with her children, they are able to tell when she is not well, and know not to bother her.

Sometimes parents fail to communicate their emotions, both negative and positive emotions, and rather show them by using their body languages. One parent mentioned that she cries when she is happy, while another parent reported the following;

> *"You will see it in my eyes, or you will see or my body language something whatever" P10*
>
> *"I don't say it; you see something is very wrong she's upset about something" P10.*

Non-verbal expression of emotions is another way of showing how one feels without verbally expressing the emotion. Culture has an important influence on experiencing, expressing, and labelling emotions (Fernández, Carrera, Sánchez Fernández, Paez & Candia, 2000). It puts pressure on how people regulate their emotions and on when, and how, they should, or should not, express their emotions. Culture influences the appropriateness of emotional expression. In other settings one might be questioned for crying when feeling happy, while in some settings this act is acceptable. Non-verbal expressions of emotions require the person, on the receiving end of the expressed emotion, to be able to decode the emotion expressed. However, the ability to decode is not equal across individuals and characteristics such as emotional intelligence and personality make it different for every individual (Edgar, McRorie & Sneddon, 2012). This way of expressing emotions needs people to have the ability to understand the emotion presented in order to respond or understand how a person feels. Non-verbal expression of emotion might pose a challenge to other children with disabilities, as they might not have the abilities decode the emotion and respond to it well. Hence, parents need to have the capabilities to express their emotions in a proper way, that is understood in the household to avoid misunderstandings. Expressing emotions promotes health relationships and good well-being for the entire family.

One parent mentioned that the reason why she doesn't express her emotions sometimes is because she is trying to protect herself from being hurt.

> *"Um, um doing that to save myself from getting hurt"* P8

The parents believe she is protecting herself by not opening up when she is going through something. However, different emotions need to be dealt with because they convey a need for action (Overall et al, 2020). That some undesired behaviours must be changed, or one needs support. Believing that she is protecting herself is avoiding to deal with underlying problems that she thinks will end up hurting her. Parents need to be informed on the importance of emotion capabilities. The benefits of how they can ensure their health as parents as well as their children. One parent in the study mentioned something different from the other participant, she noted that she doesn't talk until she has dealt with her emotions inside. That highliged that she has a way of dealing with her emotions, taking time out and come back to the situation later. Parents in this study showed that people express their emotions differently, whether verbally or nonverbally. However, they showed that they do not have enough knowledge on the importance of expression emotions and how that can help in raising their children.

5.5.2 Sub-Theme: Dealing with Emotions

Parents raising children with disabilities are at a greater risk of having caregiver's subjective internal strain (Oh & Lee, 2009). Internal strain is constant negative feelings of sadness, worry, and fear experienced by caregivers/parents raising children with disabilities as a result of the child's behaviour or physical limitations (Brennan, Rosenzweig, Jivanjee & Stewart, 2016). A number of parents in this study reported that they do have those feelings; however, they mentioned that they were not experiencing them because they are raising children with disabilities but rather because of the environment in which they were raising their children in.

During data collection, parents were asked how they deal or cope with their emotions, particularly emotions of anger, grief, fear and sadness. How are they dealing with those emotions regardless of the challenges they are going through as parents raising children with disabilities (Gupta & Singhal, 2004). They reported different things which included crying, praying to God, or talking to a person they trusted. Parents using spirituality as their coping strategy is common. A study done by Masulani, Mathanga, Silungwe, Kauye and Gladstone (2016) showed that parents used spirituality as their main coping mechanism. Using religion or spirituality (including prayer and church attendance) as a coping strategy has been linked to a variety of favourable mental and physical health outcomes (Wachholtz & Pearce, 2009). Using religion and spirituality coping strategy represents a secure relationship with God, or any higher power a person believes in, and it represents a belief that there is meaning in life and a sense of spiritual connection with others. It is also associated with higher self-esteem, better quality of life, psychological adjustment, and spiritual and stress-related growth (Wachholtz & Pearce, 2009). In terms of capabilities, this means that the parents, who use religion and spirituality as means to cope with emotional distress, show some level of an attachment. Being attached to a higher power, which is God. Capabilities of emotions, according to Nussbaum (2007), means having emotional attachments to things and people outside of ourselves which enable humans to have a valuable life.

> *"What I do is just pray. That is for me"* P9

> *"So if I pray and I finish with my prayer then I feel a bit energized."* P8

> *"…When I have not cried I don't get to be fine I need to cry and cry until everything gets down then I became fine. You can say whatever but I need to cry to be fine…" P6*

From the quote above, the participant talks about how she needs to cry to deal with her emotions and that crying is her own way of processing the emotion.

Two parents reported that they try to occupy themselves with other things like listening to music, keeping their minds busy with something else other than sitting and accessing the emotion, or even having people around to shift their focus.

> *"Yho (sigh) like I said I keep on my gospel all by my side, try to keep it, these always people children and stuff always around me these not like er sitting like now"*
>
> *"Ja, just my mind busy…"* P8

The quotes above show parents who avoid their emotions by distracting themselves from them, by practicing emotion-focused strategy to deal with their emotions. Emotion-focused strategy is when a person tries to manage emotional distress associated with the situation (Baker & Berenbaum, 2007). Emotion-focused strategies include strategies such as denial; the focusing on, and venting of, emotions; positive reinterpretation of events; and seeking out social support. Its effectiveness, therefore, depends on how a person employs the strategy (Baker & Berenbaum, 2007). According to Biggs, Brough and Drummond (2017), emotion-focused coping strategy is associated with emotional exhaustion, increased anxiety and satisfaction. As a result, it is regarded as maladaptive due to the fact that it promotes avoidance and escaping the situation. However, in the transactional theory of stress and coping by Lazarus and Folkman (1984), they mention that neither strategy is effective or ineffective and that a strategy's effectiveness depends on how the strategy corresponds to the reappraisal or situation at hand.

5.5.3 Sub-Theme: How Parents Are Accepting Love and Support from People

Raising a child with disability can be a source of stress for most parents. Parents need support, love and care from people around them. Social support acts as a mediator between stressful life experiences, family adjustment and health issues that these parents go through (Resch et al., 2010). Therefore, it was important to ask the participants how they are receiving emotional support and support from the people around them. In previous studies, parents were mostly asked whether they got support from people in general and not necessarily how they, as parents, received the support from people. 80% of parents reported that they accept love, care and support from people easily; referring to the love, support and care they receive from family and people around them. Carter, Meckes, Pritchard, Swensen, Wittman, and Velde (2004) indicated that accepted support and love is important for parents because it allows them to be able to share personal stories, feelings, frustration, and expectations.

> *"I am a very loveable person, and I like and love everybody. I like to meet people, talk to children to anyone and sometimes it's like maybe me and my hubby..."* P10

> *"I really love support that comes from people…. I receive the support and I love it.* P9

The parents that accept love, care and support from people, some mentioned that they do accept it, but have questions whether that love and support people show and give are really genuine or they are not. This shows that some people do not believe that people can genuinely show support and love.

> *"I will put this in two ways, I trust it and the love of other people I don't trust it…. because one comes close because she/he wants to look at this child …"* P4

However, one parent mentioned that she does not find it easy to enjoy love, care and support from people, including family. She mentions that she actually does not trust people around where she stays, noting:

> *"Actually I have no one that is helping me with him"* P8

> *"Actually I don't trust people around"* P8

On the other hand, some parents do receive love, support and care from the people around them but, as one mentions, at the end of the day people can be supportive and show love but it takes time to accept the fact that your child is living with disability.

> *"They do support me, but at the end of the day you can't accept it, it takes time to accept it but now you tell yourself that this is not going to pass. I should accept it. …"* P6

Parents receive and accept support, love and care in different ways. Regarding emotions, Nussbaum (2007) states that people should be able to have attachments to things and people outside of themselves and to be able to get support, love, and care, and be able to welcome it when it is presented to them.

5.6 Theme 2: Capabilities of Affiliation

According to Feldman (2012), affiliation is defined as "to bring or receive into close connections" connections of interpersonal bonds that people have with one another. Affiliation involves a process and action is needed for the bonds to take place (Feldman, 2012). However, Leary (2010) defines affiliation as the act of interacting and associating with one or more people. She further states that affiliation carries no indication of the quality of the relationship, affective tone, and how long the relationship of that nature happens. This means that it can be any social encounter a person has with another person.

According to Nussbaum (2007), in order for an individual to have a life that is worth living one must have social encounters with people, they must be able to live for, and towards, others, they must recognize and show concern for other human beings, and be able to engage in different forms of social interactions. Additionally, they must have social bases of self-respect and non-humiliation, be treated with dignity, and not be discriminated against by anyone they have an encounter with. Affiliation is important because people often affiliate to get emotional support and to obtain positive stimulation (Leary, 2010). This is what parents with children with disabilities need the most. Under this theme, friendships and respect emerged as sub-themes.

5.6.1 Sub-Theme: Relationships and Friendships on Parent Raising a Child with Disability

Close friendships are important components of well-being and social adaptation (Feldman, 2012). Participants in the study were asked about their friendships as parents that are raising children with disabilities. 58% of the parents reported that they do not have problems in making friends. However, the other 42% of parents did not find it hard to make friendships but they noted that they just do not have people they consider as friends they talk with anyone that is around them. Their reasons for not having friendships were either being too busy to have time with friends, preferring to spend most of their time at home, generally not being an outspoken person, or just being a person who prefers to not put a tag on people and call them friends.

> *"No I can't, I mean I can. Most of the time I do not have friends...I can't have a friend, I don't know how to put it, I just speak to that person."* P3

> *"Oh I am not an outspoken person but when a person gets close to me I am a person who likes to talk to a person about things that ..."* P1

Human beings are social creatures with the need to belong and be accepted is fundamental. Therefore, social exclusion can be devastating (Levett-Jones & Lathlean, 2008). The participants above highlight that even though they do not have 'friends' they are still social people. However, participant 1 mentions that she is not outspoken, which might be a factor on how she forms friendships, and that when she does talk to someone she wishes they could build a strong friendship. She wants a sense of belonging, "friendship *that sometimes you would be like my sister*". Belongingness is a deeply personal experience that involves the degree, to which an individual feels secure, accepted, included, valued and respected (Levett-Jones & Lathlean, 2008).

All the participants did not mention anything about having difficulties in making friends because of their children's conditions, however, one participant did mention that sometimes it becomes difficult because a person will ask about the child or even not understand the child’s condition. This shows that some parents do not feel comfortable discussing their children’s conditions and this may be something that hinders them from developing friendships.

Another parent reported that she had just made new friends that she sees every day, but that happened after she had to cut ties with her old friends that she had before having a child with disability.

> *“I feel that the comments about her...Wasn’t sitting well with me. So that’s why I don’t go there anymore…. I just left there and I did not go back”* P9

The participant above mentions how she did not like the comments her previous friends had about her child with disability. Parents raising children with disabilities often find themselves without friends because they sometimes get side lined by their old friends or have to distance themselves as a way of protecting themselves from getting negative comments about their children (Myers, Mackintosh & Goin-Kochel, 2009). As the participant above mentioned, she did not like the comments her previous friends made about her child so she moved to another township with her husband and never saw her old friends again. This highlights how stigma regarding disability is present in communities. It further shows how that stigma hinders parents raising children with disabilities, especially when it comes to engaging in various forms of social interactions due to what people might say about their children with disabilities. These results are similar to a study done by Thwala *et al.* (2015) which noted that parents tend to have few friends, because of the attitudes some friends have towards the children with disabilities. This can be a barrier that prevents families and parents from having an ordinary life and their capability to live a life they value is determined by how a community accepts their children.

Contrary to the other participants, one parent reported that she does not have a friend or someone she can say is her friend because she was disappointed by her last friend and she now she refers to God as her only friend:

> *"And that one friend also disappointed me, so the only friend I have is God, he's my best friend"* P8

The participant mentions that she was disappointed by a friend then decided to befriend God but she doesn't mention whether the disappointment was because she has a child with disability or not. She is now using spirituality and religion as a replacement to having friends. Spirituality and religion is used by people to deal with their emotions and it acts as a source of comfort and something that they use to obtain consolation, security, and guidance that some people would get in friendships (Exline, Yali & Sanderson, 2000).

However, not everyone may consider using spirituality and religion as a replacement of having a friend or developing friendships. Some people may see God or any higher power as distant (Exline, Yali & Sanderson, 2000), than having an actual friend they can see with the naked eye. According to Nussbaum (2007, 2011) on affiliation capabilities on her central human capabilities, she states that as human beings, people should have the ability to live for and to others, that requires people to be open to creating friendships and relationships to live for and be in however, when they get disappointed by friends that demotivate them to get into new relationships and friendships where they would find comfort and be able to have something to live for and end-up seeking other avenues to find comfort.

According to Leary (2010), people are generally not only interested in being with other people, or just developing connections, but they also want to show them that they have something to offer. Furthermore, people often seek to relate and get others to relate to them. People seek relationships where they will be valued and accepted. Parents in this study were asked how they view the people that surround them, how they show concern for each other, and how much they value them. The participants showed positive reflections of how they perceive people around them, noting the love and support they are getting from them. One participant mentioned how her neighbours look after her house when she goes home to another province or even when her child is playing outside and she is inside the house. While other parents mentioned the quotes below:

> *"I feel comfortable; I feel loved"* P9

> *"yho they are very supportive, they support my child's situation and they support me so much as well. Sometimes when the ambulance comes late a car from other neighbours comes out to take me to hospital"* P4

The above participants appreciate and value their neighbours as they mention how supportive they are of them, not only as parents but as parents of children with disabilities. They are open to helping each other in times of need as a way to show that they care about each other. One participant says she's comfortable, feel loved and that shows a sense of belonging within the neighbourhood. Sense of belonging is a personal experience where an individual feels secure, accepted, included, valued and respected by the people around (Levett-Jones & Lathlean, 2008). Participant 4 mentions getting support from their neighbours even in transporting her children to hospital during emergencies. This shows that the neighbours do show concern for other human beings and that their relationship does not only include interacting with one another but rather helping each other in times of need.

The two parents below mention that they do not have much to give but when their neighbours are in a situation where they need something from them they would talk to them, and advice where needed.

> *"Like I don't have (something) to give for (to) them but we love each other here and if they want to talk to me about something a problem I can express tell them my feelings or what they must do.*" P5

> *"Talking to her, and sit with her. A person can be healed with words"* P6

Other parents mention how they would go beyond just talking to their neighbours and offer what they have to help them.

> *"…the neighbourhood we have is looking at each other, if my neighbour is not there I look after her house and make sure nothing wrong happens…. We give each other things to cook. I mean my neighbour would not go to sleep without food while I slept with food."* P4

> *"I will share the rice with you, the sugar whatever or you can come here I will make porridge this is for children this ja, this is for this because you don't know what is happening tomorrow that is always like I'm saying fear is always there"* P10

The above quotes show that participants have the capabilities to show concern for other human beings and have the capability of having social interactions with the people around them. They show they are able to be a source of support to other people, even when they do not have much to give them other than offering to listen to the person. Having positive relationships with the people around them is important because the parents can ask for help from their neighbours, for their child, anytime. However, on the contrary, one parent reported that she does not have the love she is supposed to have towards the people that are surrounding her. She mentions that her community members do not support each other and she has no one supporting her with her child, people do not support her even on her business

> *"The love that I am supposed to have I don't have…It's so hard to show them that you care but sometimes they come and ask here at the gate for bread, for sugar and if I have I give, that's how I show appreciation."* P8

She also mentions that it is hard to show people that she cares or appreciates them because of how people in the community are towards her. This shows that not all communities are the same, and not everyone is willing to support and develop friendships and relationships.

5.6.2 Sub-Theme: The Respect Parents Get from the Society

Rewakowski (2018) states that, respect is both a noun and a verb. As a verb, respect is used as an action of giving attention, to feel or show honour and esteem, to avoid intruding or interfering with. As a noun, it is a feeling of high regard, esteem, and a state of being held in honour. People are taught respect from a very young age as they are taught to respect parents, older people, and teachers, as well respect each other (Dillon, 2003). Respect honours inherent worth in the way that respect is felt and shown toward others simply because they are human beings (Rewakowski, 2018). A person does not have to hold a certain position to be respected or to feel respected. However, Dillion (2003), states that people often develop great respect for people they consider exemplary and lose respect for those they do not see as worthy of the respect. However, the duty to respect is not related to a person being a means to an end, but rather it is an acknowledgement of inherent dignity and worth, which is what Nussbaum (2007, 2011) argues, that everyone is worthy of respect.

All humanity should have freedom and opportunity of having the social bases of self-respect, non-humiliation, to be treated with dignity, to be a human whose worth is equal to others and not be discriminated against in any form. Respect is linked to affiliation because when people respect each other, they develop a unity and have connection. Participants in the study were asked about respect and whether they feel respected by the people around them. To explore their capabilities of affiliation and how that facilitate in helping parents ensure health and well-being of their children. Participants' responses were mostly positive with a few that had negative reports. Responses showed that participants respect the people around them and appreciate them for the things they have done and how they have treated them.

> *"Yes they respect me because I respect them. And I know that I wouldn't say something in a person because that people will be hurt"* P1

> *"I respect them and I love them, they also love me*" P4

The participant's responses show that they do get respected and loved. According to a study done by Parse (2006), being respected gives individuals the ability to move with confidence and dignity which are all inherent in the quality of life of humanity.

However, one participant mentioned how she once had a fight with a woman in the community because she was swearing at her child. Swearing does not show respect towards the parent and the child, and instead shows that they were treated in a non-dignified manner. Furthermore, the actions make it seem as though the child's worth is not equal to that of other people because of their disability.

> *"So I told myself that we are going to fight because I tell them that whatever they would say I do not have a dustbin for him, I will be separated by death to him."* P6

This shows that people do not always give respect to other people and it is evident that there is still disrespect shown towards people with disabilities (Thwala *et al.*, 2015). In most African countries, disability has been associated with being hopeless, helpless, and is seen as a curse. This belief and culture has had an impact on how people accept those with disabilities (Thwala *et al.*, 2015). However, all the negative attitudes that exist towards people with disabilities are misconceptions that came from a lack of proper understanding regarding disabilities and how these disabilities affect the functioning of the person (Thwala *et al*, 2015). These misconceptions then result in both children with disabilities and their parents being discriminated and seen as less dignified than people. Participants were also asked if they had ever experienced any form of discrimination from their communities and, while their responses did not show that they had experienced it personally, they did report that people made negative comments about their children.

> *"Yes, sometimes, not discriminated man, sad. Sad because there are so ignorant, there even if I wasn't [in] their shoes, I would look at it like maybe in other perspective"* P10

The parent mentions that people are ignorant and that, if she was in their shoes, she might look at her situation differently too. During the interview, the participant mentioned that sometimes it is difficult to make friends because of how people react to her child. The following quotes are from the participant who says people are ignorant of what they say about her child (who has Prader-willi syndrome):

> *"The people don't understand the condition then they will look at you like yho why your child is like this"* P10

> *"She's big girl, why don't you um control her eating and why no I blame the mother or the father or the, they don't know"* P10

In most communities' people still do not know how to react when they see a person with a disability which sometimes results in them staring or passing unpleasant comments to the parents and the child with the disability. However, this is no excuse to not respect other people and treat them with humility and respect.

Another parent mentioned that she sometimes makes excuses about her child's behaviour in settings where people do not know his disability. This shows that people look at her, and her child, differently and in a way that makes her uncomfortable which then forces her to make excuses to cover up for her child's behaviour:

> *"Er discrimination because um they don't know his illness"* P10

> *"No I just say he got his illness and I forgot to give him his medication…"* P8

The way people react to people with disabilities might not necessarily be seen as discrimination but it does raise questions regarding how they understand people who are different from the expected.

5.7 Theme 3: Capabilities of Control Over One's Environment

Control over the environment is one's ability to have control of the things that have an influence on the individual, political decisions, and material things. According to Nussbaum's (2007) central human capabilities, citizens should have an ability to participate effectively in the political decisions that govern their lives. From the capabilities perspective, control over one's environment has a relationship with poverty, having freedom in terms of your environment, the things that influence your life, and how a person is depended on them has power over whether the person experiences poverty or not (Curtis & Cosgrove, 2017). In South Africa, the Bill of Rights passed in 1996 states that individuals over the age of 18 have the right to vote for their choice of political party that will govern the country democratically. This is a means to get involved in the governance of the country. Participants in the study were asked about their involvement in politics and activities that take place in their communities.

Most participants reported that they do not participate in community activities because of time issues, noting that they have house chores to do and they need to take care of their children:

> *"Who is going to fetch her, who is going to take her to the toilet, who is going to do that. So I must always think about her whenever I do something"* P9

> *"… maybe I don't have someone to leave him with or I have to go with him and think that when we get there he will make noise, my son makes noise and people won't hear and I think no let me just not go"* P6

In the above quotes, participant 9 expresses that she would like to participate in more community activities but that she needs to take into consideration the fact that she has to be home most of the time to take care of her child with cerebral palsy. On the other hand, participant 6 cannot always go to community meetings because she does not have someone to look after her son. Another participant mentioned that she feels like she does not fit into community activities like meetings.

Other participants mentioned that they do get involved in community activities like meetings. However, as much as they get involved, one could argue that they attend them but for a limited amount of time and if the meetings are not going to take a lot of their time. Because the parents did not mention participating in any big community roles, besides voting during election time and attending meetings, which some of parents did not even attend. One parent mentioned that she was once appointed for a role in the community but she could not take it because of her responsibility to take care of her children:

> *"…there was this meeting of the houses then they were looking for someone for the wards… a few people wanted me, I say no man I can't do that, not that I don't want to ...These always things, look out this children of mine…"* P10

The participants reported that they are not involved in politics, due to various reasons like politics being complicated or too much frustration at the political fights that sometimes take place. However, they mentioned that they do practice their right to vote for who they want to govern them. Based on human capabilities, the participants do not fully participate in political choices that govern their lives if they are only limited to voting when it is time to vote and are not able to take on big roles that have an influence on their lives and their children in societies, due to their responsibilities.

In terms of material things, only 5 out of the 12 parents own houses while the others stay in shacks. The parents that are staying in shacks mentioned that they do not like staying in them, and they spoke about how challenging it is to raise their children in those environments. Of the parents below, one reported that she applied for a house a long time ago and that the people she applied with now have the houses while she was told that she will have to wait. Another participant mentions that living in the shack she is staying in is more stressful than actually taking care of her child. These results confirm what Green (2007) reported from the study she conducted about neglected aspects of raising a child with disability, that mothers are more likely to experience the burden of caring for a child with a disability from of socio-cultural constraints than emotional distress, access to proper housing gets in a way of parents making sure that they are taking care of their children.

> *".... I did again submit the form so it surprises me that my child's house is not written as a house for someone who is disable. So I will wait like other people whenever to have a house…"* P6

> *"I think if we would have been in a proper house it wouldn't be so difficult you see, but now because of this we have to fix the roof, we have to fix this, we have to fix that. …I think this is also more of a stress than looking after them"* P9

The participants were also asked about their employment status and 50% of the parents reported that they are unemployed. Three participants reported that they are working while one reported that for two months a year she works part-time and another volunteers and gets paid for it. The rest of the parents reported that they are unemployed due to different reasons. The most common reason for their unemployment is that they need to take care of their child with a disability.

> *"I can't work because I must look after Hope and she's at school. I must always be here. I must give her, her meds see that she is well and she doesn't get…"* P10

> *"I am staying, I signed that I will look after my child. Because when I look outside and see that things are not good, work is scarce but I never wanted one, so my work is putting people in the yard so that I will get money and be able to put bread for my children in the table, because I know their lives needs me, they will not be okay sometimes while I am working I won't able to escape in a white person (work) saying my child is sick. Because sometimes other white people do not do such things. I am staying, I am not working"* P4

The above quote is from a parent who is worried about not being able to attend to her child emergencies due to being employed, she mentions that some employers would not accept such things. This is similar to a study done by Thwala, Okeke and Dludlu (2018) about the experiences of raising a child with disability. Their study noted that parents would rather quit their jobs to take care of their child with a disability either because they cannot afford to pay someone to look after the child or because their child's behaviour might not be understood by someone else.

Furthermore, some parents are worried about who will take care of their child when the child returns from school and they are still at work. They prefer not to work in order to ensure that they will always be available for their children. A study done by Brandon (2007) supports these result, parents raising children with disabilities cannot rely on other people to take care of their children because most people that could look after them are most likely to be at work too or be in a process of looking for a job, and accessing suitable child care for children with disabilities can be difficult. In a study done by Gray (2003), where he was comparing gender roles between mothers and fathers raising children with disability, mothers reported that they have accepted career limitations that come with raising a child with disability, despite the fact that a number of them resented it and felt it was unfair.

This was not the case for this study as the parents, most of whom were mothers, preferred to stay at home and look after their children and not work. One parent in this study mentioned that she cannot work because of her sickness — she has a memory loss condition and is also claustrophobic so she cannot operate in places where you need to scan to get in. She also mentioned that she needs to be home when her son comes back from school.

The parents of children with disabilities have the right to be employed just like any other person, however the freedom and opportunities are not created for them to be able to hold employment. According to the employment equity most jobs in South Africa require a person to work 8 hours a day during weekdays. Working full hours is not ideal for parents raising children with disabilities who need to be at home when their children come back from school. This shows that parents' abilities to gain some financial freedom are restricted by policies such as the number of hours worked per day (Thwala, Okeke & Dludlu, 2018).

5.8 Theme 4: Capabilities of Bodily Health

According to the WHO (2011), health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. For one to be healthy, one does not need to have a disease that needs to be treated with medication but their state of physical, social and mental well-being needs to be taken into consideration. Nussbaum (2007, 2011) states that bodily health is one of the central human capabilities that all human beings need in order to have a life that is worthy to be valued by individuals. Bodily health is being able to have good health, being adequately nourished and having an adequate shelter to stay (Nussbaum, 2007, 2011). Participants were asked questions that aimed to explore their health and the choices they make about what they eat and what conditions they live in. Most participants believe that they are healthy and note that they only sometimes get sick with fever and colds and go to the clinic. They further noted that this does not mean they are not healthy.

> *"Because I sometimes have fever once and go to the clinic and be fine I think (I'm fine)"* P1

This quote shows that the participant only recognises physical health as an area to be associated with health. The two participants quoted below note that they are not healthy and they particularly believe that they are not healthy emotionally. One mentions that she sometimes finds it hard to wake up because of the emotional stuff she goes through. She also mentions that she sometimes has to force herself to do some things at home. The other one reports that taking care of her kids has affected her. Both participants acknowledge the mental health component in the WHO (2011) definition of health and note that even when they are physically healthy, their mental health is affected by their emotions and their responsibilities as parents raising a child with disability.

Participant 8's response also shows the challenges that parents face including being overwhelmed with their lives because of what they are going through. Participant 4 mentions that the challenges she faces end up making her not feel okay because she is constantly thinking about her children. According to Beresford, Rabiee and Sloper (2007), parents of children with a disability suffer from exhaustion and stress due to the amount of care they need to give to their children with disabilities and their entire household simultaneously.

These results reflect similar results from a study that was conducted by Thwala *et al.* (2015) which stated that emotional distress and depression are some of the challenges that are common in parents raising children with disabilities. The continuation of these results from parents raising children with disabilities show that they struggle to manage their emotions and physical exhaustion. This shows the need to help strengthen the parents' capability to adapt and manage themselves when dealing with their children with disabilities in order to improve their subjective well-being and to have both a good interaction between their mind and bodies and to be able to ensure the health and well-being of their children (Huber, Knottnerus, Green, van der Horst, Jadad, Kromhout & Schnabel, 2011):

> *"Because these sometimes I don't feel er I want to get up today, like I am going through a lot of things emotional stuff and that stuff that's making me weak"* P8
>
> *"Because you see the life of my children has affected me so much, because now I would say the person who is not right is me…. Because the person they are taking care of is me, when you face challenges your life ends up not being okay not knowing what is going on because you think too much, maybe it is thinking it. But the way I think about it, I think I am not right"* P4

Participants were asked about the food they eat and whether they consider it to be healthy or not in order to explore if they get nourishing food for both themselves and their children. Parents mentioned that they try to get their families to eat healthy, however, with the little money they have, most of them mentioned that they buy essential things and then see if they can add a few healthy things. Money was what hindered most of the parents in getting healthier food for their families. Previous studies done on parents raising children with disability acknowledged financial struggles are always common (Thwala, 2015; Vanegas & Abdelrahim, 2016).

> *"we have to make something only papa for them then these nothing with the papa, sometimes they ask sugar on the papa and I say these no sugar you see"* P5

> *"So I can't afford to buy healthier staff because I'm limited you see because we don't have that kind of money to buy all that staff*' P9

> *"So there isn't like something that I bought like tomatoes, or cucumber or lettuce that is like a specialty for us. Sometimes there must be potatoes, rice, pieces of meat, mince, spaghetti just to have food on the table"*. P8

These participants above show that their focus is not on how healthy the food is but rather on giving their children something to eat. They do not have the freedom and opportunity to decide on how healthy or unhealthy the food is due to the financial challenges they face — to them having just food is enough. When compared to people who have enough healthy food to eat, not consuming healthy food can result in poor health for both the parents and children (Nielsen, Garasky & Chatterjee, 2010). Therefore, the bodily health of both the parents and children lacks the freedoms and opportunities to be adequately nourished because of financial challenges.

Participants were also asked about the places where they stay and whether they have their own properties or they live on someone else's property. Some reported that they have their own houses, while others stated they were staying in other people's houses. Two parents reported that they are renting shacks at the back of people's houses, meaning they need to pay with the little grant money they depend on. Both of the parents were not happy about their living conditions, and one even mentioned that she stresses more about the place she is than she does about raising a child with a disability. Another noted that she is living close to a smoking spot and pays R700 rent from the R1700 she gets for his child's disability grant.

"I think if we would have been in a proper house it wouldn't be so difficult you see, but now because of this we have to fix the roof... we have to fix that. Its ...I think this is also more of a stress than looking after them" P9

"We staying, waiting for anything, what can I do, what can we do, where are we going to go, when you do not have a place to stay you are forced to endure anything. Even though yes it is not fine" P6

Additional Themes

5.9 Theme 5: The Kind of Relationship Parents Have With Their Children With Disabilities

It is often said that "blood is thicker than water". This phrase is used in many societies and suggests that through any hardships, families joined by blood can withstand anything together. Within families, these bonds are mostly noticeable in parent-child relationships, when the relationship between the parents and children is strong and positive (Scharp & Thomas, 2016). However, not all relationships between parents and their children are positive or strong.

Parent-child relationship is the quality of the emotional connection between a child and their parents (mother and father or significant parental figure) and the degree to which this connection is mutual and sustained over time (Lezin, Rolleri, Bean, & Taylor, 2004). Howe (2016) states that parents' sensitivity, emotional connection, and how parents respond to their children depends on their ability to accurately recognize, understand and interpret their children's behaviour (body language, facial expressions and speech). However, in cases of children with disabilities (not all disabilities), their communication abilities might be compromised due to a number of functional and sensory impairments. This makes it difficult for both a child and their parents to have a good relationship. Howe (2006) adds on and states that parents are not only required to be sensitive but also be able to read their children's mental state and be able to establish a good relationship with their children with disabilities. Parents in this study were asked about their relationships with their children with disabilities. Most participants reported that they have good relationships with their children.

> *"We like writing, playing and taking pictures of each other, we really love each other, he is the one person I am in love with in the house*" P3

> *"Yho it's really beautiful, it's really beautiful as a result you would see if she would get in, she would greet you last and greet her mom first and jump to the shoulders and hug her mom…*" P4

Regardless of the challenges parents face while raising children with disabilities, most parents show that they have great love for their children. They still play and show love to their children regardless of their children's condition. These results are similar to the results from a study that was done by Myers et al. (2009) where he found 9 positive themes on how children with autism have impacted their parents' lives. In the study, parents mentioned how their children's conditions have enriched their lives and the love they have for their children.

> *"My child would say 'mama mama' while I'm crying, trying to comfort me, hugging while I'm crying then I would feel like yes now everything feels better I am alright.*" P6

The above quote is from a parent who explains that she deals with her emotions by crying and this is what her child does when he hears her cry. The child has an eye-sight and physical disability, however, he can hear that his mother is crying and tries to comfort her. This shows the relationship they have it is not one sided and even the children connect with their parent(s). One would argue that parents have this kind of relationships with their children because of the hardships and challenges they went through together as a child and a parent, which then makes them to have a strong relationship, knowing that no one else is going to take their roles as parents. The parent below speaks of how it is hard to accept that a child has a disability but telling yourself that this is still your child, and knowing that nothing is going to change about their condition, helps:

> *"...but the at the end of the day you can't accept it, it takes time to accept it but now you tell yourself that this is not going to pass I should accept it these nothing that will change it will always be like this, we are going to be separated by death with him. So what is important is to tell yourself that this is your child in whatever that is happening in life.*" P6

> *"So you don't have another option but to tell yourself, even when things are going up tell yourself that this is your child at the end of the day"* P6

One parent reported that sometimes her child makes her so angry that she finds herself being negative towards him. This is the only parent that had a negative report about her relationship with her child. However, she mentions that she becomes negative to her child when she wants him to change his behaviour and so her reaction is her way of trying to instill good behaviour in the child.

> *"You know at the moment it's not good, because er he's disobedient and I don't like it, and that behaviour of him, he doesn't want to listen when I talk and that behaviour is starting to build up inside of him. I told him over and over again I hate you I hate you, I want to get rid of this child I don't like him, I don't want him, like that but most of the time its just like I say these things so I want to see his reaction if he doesn't want to change maybe, maybe he doesn't want to make me feel different*" P8

"Because he thinks more of the people outside than what he thinks of his mother. That's what making me angry about him" P8

The parent shows less responsiveness and overprotective of what the child takes from the outside people. Which are both characteristics of a weak bonding because of the affectionless control presented by the parent (Rose, Roman, Mwaba & Ismail, 2018). Based on parenting styles, the parent is using an authoritarian parenting style. Authoritarian parenting style is used by parents who are characterised with high demand and less responsiveness. This type of parenting style values obedience and the use of forceful measures when the child does not follow what the parents want (Carter & Welch, 1981). Based on the Woolfson and Grant (2006) study, authoritarian parents experience stress, especially when the child is a generally difficult child.

Availability of parents to their children has an influence on the how relationship between parents and their children turn out to be. Raising a child with a disability requires parents to be constantly available to their children in order to ensure their health and well-being (Woodgate, Edwards, Ripat, Borton & Rempel, 2015). Some parents in the study reported that they are not working, or participating in community activities, because they want to be available to their children. This is something that allows the parents to bond more with their children and have close parent-child relationships with their children.

Parents' availability can be viewed as their strategy to ensure that their children are well taken care of. Parents' availability to their children enables parents to learn about their children and to be able to tell when a child is not well or when they have experienced something bad at school or in the community. This is a good strategy not only for ensuring health and well-being but also for creating a strong between parents and their children. Two parents reported the following about being available for their children:

> *"So I will easily notice when they are sick, I will easily notice when they are not themselves, I will easily notice if something is wrong with them …So. I'm so close to them I will easily notice if these something wrong"* P9

> *"He is very forward, you can easily see when he is not okay, and then I see that he is not okay. You can even see that something is coming before he actually gets sick. I quickly see him*" P3

The parents in this study did not mention that they raise their children with disabilities any different from the ones that do not have disability. They referred to their children as one, not differentiate who has the disability with those who do not have disability. The parents only differentiated when the interviewer asked a specific question to either a child with disability or not. While this could mean that they do not treat their children differently, it must be noted that this was not explored. It was not explored because the objectives of the study were not to see how parents treat their different children, but rather the strategies they use to ensure health and well-being of their children.

5.10 Theme 6: Strategies/Facilitators Used to Ensure Health and Well-being

Strategies are the course of action taken to deal with a situation (Mintzberg, 1987). This study focused on the strategies parents use to ensure the health and well-being of their children. Parents are parents because they have children and they come to understand their roles as parents both by once being a child, who observed their own parents, and by their interactions with their own children (Park, Jeong & Zimmerman, 2008). The key words here are having (having a child), being (being a parent to that child), and lastly, doing (interacting with the child) (reference). All of that is different for parents raising children with disabilities. Yes, they have a child, but not a typical developing child and when they were children, and observed how parenting was done for them, it was not parenting for a child with disability. This makes the last part — doing their role as parents raising children with disabilities — more challenging. In this study, parents were asked about the strategies they use to ensure that their children are healthy and have a good well-being.

5.10.1 Sub-Theme: Encouragement

As disability is still not received well in most communities, people are not used to seeing people with different disabilities. Most parents find themselves having to continuously encourage their children, and comfort and assure them of their love. Parents in the study mentioned that they keep encouraging their children when people say bad things to them:

> *"...I used to be worried because when she was playing on the streets there were children who were saying we shouldn't play with so and so because she has a leg like this…Then she would come to me sad, and I used to tell her no do not be worried because your family loves you more especially me. Your mother loves you do not mind being loved by the people from the outside" P*1

> *"So I told her don't worry, they don't know what they are talking about, but I could see in her face that she wasn't happy with it…"* P9

Parents do not only have to encourage their children, but they also have to encourage themselves. One parent mentioned that she has to keep encouraging herself to accept the child in order to be able to be a good parent to her child. Others mentioned praying and going to church as their source of encouragement to keep them going and to deal with their emotions when overwhelmed.

5.10.2 Sub-Theme: Availability

Raising a child with a disability requires parents to be constantly available for their children, for different reasons, in order to ensure their health and well-being (Woodgate, Edwards, Ripat, Borton & Rempel, 2015). Parents in the study mentioned that they need to be home most of the time in order to be with the children and some parents even decided that they will not have jobs so that they can always be available. One parent reported that she accommodates people on her yard so that she can make money since she is not working:

> *"I can't work because I must look after [her child's name] and she's at school. I must always be here. I must give her, her meds see that she is well and she doesn't get hurt ..."* P10
>
> *"...Because I know their lives needs me, they will not be okay sometimes while I am working I won't able to escape in a white person (work) saying my child is sick..."* P4

It is evident that parents raising children with disabilities sometimes have to compromised and not work to be able to with their children. To ensure availability to their childrens needs. That is understable because it is their way of making sure that their children's health and well-being is not compromised. However, this highlights the challenges that they experience, considering that raising a child with disability comes with added cost in the household. This does not only highlight the financial challenges but also how parents raising children with disabilities are not provided with abilities to have control over their environment. Working hours and working environments that do not give parents the freedom to work and also enhance their children's wellbeing. There is a need to expand workplace flexibility, to help parents place their children in high-quality child care, and help parents train for, find, and be in paying jobs to provide for their children (Heinrich, 2014). These strategies need to be supported by the workplace and other institutions that aid in parents ensuring that they provide great care for their children.

One parent, who is volunteering at a school where her child studies, mentioned that being always around her child allows her to know that she is always well. During the week they both go to the same school and during the weekends they both are at home. Her work allows her to constantly be around her child which is not something most parents raising children with disabilities would experience:

> *"...I am always with her, I am here at school now and she is right in front of me in school… on Saturdays I am not at school she's also not at school, we are together at home"* P1.

In South Africa, it is normal for children to be raised by their grandparents while parents move to bigger cities to look for jobs to support their families back home (Schatz, 2007; Mtshali, 2015). However, one parent on the study mentioned that even though she could have her own parents take care of her child back home, she made the decision to look after her child herself:

> *"...I told myself that in life I have my parents in Eastern Cape but I told myself that I want to stay with him"* P6

Availability is not only their strategy in terms of looking out for their children's health but it also includes other things like being there to make sure that their children are fed, bathed, and assisted when they need some assistance (this includes help going to the bathroom for those children who use wheelchairs). One parent reports the following:

> "*On a daily basis, feed her, bath her, take her to the toilet when she wants to go"* P9

Another participant mentioned that she taught her child how to do things on her own to make sure that she is independent and is at least able to do basic things. However, that is not possible to every child as it depends on the severity of the disability.

> “*...I taught her to be able to do things for herself so that she won’t be depended, because it can happen that I die while she is still that young and be a burden to other people I don’t want that”* P1

Teaching her child to do things for herself is a strategy that does not only focus on the now, but also prepares the child for the future. For the parents, their availability is important because it gives them an opportunity to ensure that their children’s health and well-being is not compromised. They know all the details about their children’s lives and this strengthens their parent-child relationship.

5.10.3 Sub-Theme: Support

Parents get support grants from the government in the form of a grant, disability grant, or care dependency grant. Those who receive the grant report getting R1, 700 per month. The parents mention that this grant helps them a lot when taking care of their children. They say it is helpful because they are able to do basic things like buy food, clothes, and pay rent. Others use some of the money to pay for transportation for their children to go to school. All of the parents that receive the grant mention how helpful the grant is to them and their children:

> *“…I must pay his transport with that money and then I have to buy anytime like shoes, school stuff and clothes for him and I have to provide for the month also food”* P8

One parent mentions that she has nothing but the grant to support her financially as she is not working or staying with someone who works. She reports the following:

> P6: *“It is helpful because we rent with it, we buy food even with it”*
>
> Interviewer: *“If it was not there what would you be doing?”*
>
> P6: *“There wouldn’t be any other way”*

She buys food for her child and herself, as well as diapers because her child is dependent on them. She also pays rent for the shack they stay in.

However, the parents do say that the support grant is not enough to cover everything they need for them and their children:

> *"I find it helpful but I mean it don't cover everything"* P9

Financial support is not the only support needed by parents to be able to raise their children. According to Vanegas and Abdelrahim (2016), parents also require emotional/social support, educational support and instrumental support. Emotional support promotes, and gives parents, the feelings of being affirmed and appreciated. It can be in the form of informal and formal support from close people and family. Instrumental support provides services to the family which includes medical services and screening, and they are normally done in homes or in hospitals settings. Educational support includes services that provide information about child development, diagnosis and treatment options and they are offered at home or in health facilities. (Vanegas & Abdelrahim, 2016)

The parents in this study reported that they get informal emotional support from close friends and family. Emotional/social support is another strategy that parents use that helps them manage their upbringing of their children. The support they get is a strategy to ensure the health and well-being of their children because when they face challenges they can quickly talk to someone when they are in need of anything. One parent mentioned that she has in-laws that she considers to be her support structure as she can go to them for anything she needs. Another parent mentioned that she has a sister she can talk to when she has a problem or just wants to leave her child to quickly go and fetch medication for her son or run to the shops.

> *"...even now you see tomorrow I am going to Red cross to fetch pills for him, I will leave him here sleeping then leave the keys to [mentions the name of her sister's child] mom when she wakes up she will come and look after my child…"* P6

She also mentions how she can call her brother's wife whenever she needs because she knows they will help her:

> *"Family when I have a problem I can call my brother's wife to talk to her*" P6

Social and emotional support is important in influencing the way parents cope or deal with the stress of their children's condition. Wojtas, Oskędra, Cepuch, and Świderska (2014) found the existence of a correlation between the level of social support received by parents and how much better they cope with challenges of raising children with illnesses. They state that the support allows parents to look optimistically to the future, knowing that there is help available when they are in need.

One parent mentioned that she recently attended a support group that was provided by the school that her child attends to. She reported how the support group made her to feel, and making her to realize that she is not the only parent raising a child with special needs. According to Carter et al. (2004), apart from receiving social support in the sense of hope and comfort, support groups also allow parents to gain information about the different ways to raise their special children.

> *"But like the support group we were in it was my first time but I feel like in yho a whole lot better because it isn't just me*" P10

Being able to accept and receive support acts as a strategy to ensure the health and well-being of their children, because without the support they are getting from the government, family and friends they would experience more emotional/social distress which would not be good for their well-being. Furthermore, being able to accept and receive the support from family and friends also speaks to their capabilities of affiliation. Nussbaum (2001, 1997) states that people should be able to live with, and toward, others, and have the capability to have social relations and interactions with other people. This capability allows the parents to share their burden and seek strength when they need it from people close to them. This is a strategy that benefits both the children's and the parent's health and well-being. Human beings need to be social in order to strive

5.11 Theme 7: Barriers That Prevent Parents From Ensuring Health and Well-being

5.11.1 Sub-Theme: Finances

Resources, such as time or money, have an important role in ensuring the personal well-being of both the child and the parent (Burton, Lethbridge & Phip, 2018). Parents on the study were asked about the things that act as a barrier (things that hinders them) between them and ensuring health and well-being of their children. The question was asked to explore what they perceive as a blocking barrier from being entirely capable from taking care of their children. Finance was the issue that was the most common response among participants as finances have an influence on the food they buy for their children as well as their transportation to hospital:

> *"First of all money, house, transport also because I mean sometimes we have to get to the hospital and then we have to take three to four taxis and its difficult with a wheelchair... sometimes I have to cancel appointments because I can't make it because of money."* P9

> *"If I can get the finances, then I can buy him healthy stuff to eat but for now we have to eat what I can afford you see, I know he needs healthy stuff because he's on medication but I cannot afford it"*. P8

> *"...sometimes even when the appointments I must go and borrow some money… I must go borrow just this morning, yesterday Hope these was a meeting she must bring cool drink 2 litters cool drink and I don't have the money"* P10

One would think that because most parents do receive support grants for their children, finance would not be much of a problem. However, the support grant becomes their only source of income which means that everything in the household depends on the support grant — food, clothes and even school transport for the child. In the study, parents do mention that the money is not enough and that it doesn't cover everything the children need. Some parents end up having to borrow money in order to do other things and they even have to cancel hospital appointments because they do not have the money to travel. As a result of the financial issues, some parents wanted to seek employment to add an income to their support grant funds, but others noted that working, or looking for a job, was not an option because they had to be home to look after their children.

In a study conducted by McNally and Mannan (2013), parents spoke about lack of money for both healthcare and necessities as the key challenges they are facing. This proves that many parents struggle to ensure the health and well-being of their children due to a lack of funds. McNally and Mannan (2013) argue that financial challenges in parents raising children with disabilities are a result of their lack of employment and this goes back to control over the environment capabilities as parents do have the right of employment but that employment does not allow them to have functionings that are valuable to them. Most jobs require people to work from 8am-5pm and parents raising children with disabilities need to be at home to look after their children, especially when they do not have people to look after the child while at work. Taking care of a child with disability limits the chance of parents going out to look for jobs, which leads to the challenge of not having enough finances to do the things that are necessary for themselves and their children with disabilities (Mitra et al., 201). Also, work can have both positive and negative effects on their children (Heinrich, 2014). For example, employment lifts family income which has many beneficial consequences for children, and working parents can be positive role models. On the other hand, work can reduce the amount of time parents spend with their children, expose parents to severe stress that spills over into family life.

Not having money also affects the places the parents stay in with their children. Two parents mentioned that the places they stayed in were an issue that prevented them from ensuring the health and well-being of their children. The two parents who stay in backyard shacks reported that staying in the shack is more stressful than other things. The parents need proper housing for themselves and their children in order to be safe and be able to ensure the health and well-being of their children.

The one issue that was outside the need for finances, was the ability to control cleanliness in the community. A parent with a child who has an opening below the neck mentioned how she cannot always control the environment in which the child's plays in. People in the community around where she stays just litter anywhere and dust and dirt has an effect on the child’s opening, so she constantly needs to make sure that she cleans the opening and restricts her child from playing in other places.

Health and wellbeing of children needs parents to be able to have some control over their environment, if providing for their households is infringed by not having enough money or means of getting an income but still be available to their children then capabilities on control over the environment is not being met.

5.12 Summary of Data Analysis

Seven themes emerged from data analysis, four pre-determined themes from the human capabilities on how parents use their capabilities, the kind of relationship parents have with their children, strategies that facilitate parents in ensuring health and well-being, and barriers that prevent parents from ensuring health and well-being of their children. On the capabilities of emotions, some parents show that they have capabilities of emotions however others avoid their emotions and cannot express how they feel. Parents reported that they do not have problems making friends, but hardly regard people as friends. Rather, they just go to anyone close to them for friendship.

The data also showed that in some societies people with disabilities are still made fun of and are not treated like everyone else. Most parents had one common report about finance being their barrier that hinders them from ensuring the health and well-being of their children. Money had an influence on what they ate and the places they stayed in. Most parents in the study were staying in shacks and reported that they could not eat healthy food because they could not afford to buy it. Half of the parents in this study were also unemployed either because they could not find jobs or because they prefer to stay unemployed so that they are able to stay home and look after their children. Parent mentioned that they also cannot participate in politics because of their responsibility to take care of their children.

CHAPTER 6

CONCLUSION AND RECOMMENDATION

6.1 Introduction

This chapter presents the summary of findings, recommendations for future research, methodological limitations and conclusion of the study. This study focused on exploring strategies used by parents to ensure the health and well-being of their children with disabilities.

This study was an exploratory study that used qualitative methodology and semi-structured face-to-face interviews as the main method of data collection. After the completion of the interviews, all the data was transcribed and the data was analysed using thematic data analysis.

Themes were identified in that process and they were either supported or argued against by relevant literature from previous studies on disability and parenting.

The research questions that were important to be answered by participants were:

1. What are the strategies used by parents to ensure the health and well-being of their children living with a disability?
2. What is the nature of the relationship between the parent and child with a disability?
3. What are the barriers that parents face when caring for children with disabilities that enhance the parent-child relationship?
4. How do parents use their capabilities (bodily health, emotions, affiliation and control over one's environment) to ensure the health and well-being of their children?

By answering the above research questions, the study achieved the following:

1. The study explored the strategies that parents use to ensure the health and well-being of their children with disabilities, which included making sure they are constantly available to attend to their needs.
2. The study explored the nature of parent-child relationships between a parent and a child with a disability. Most parents in this study reported to have a good relationship with their children regardless of the disability and the challenges they encounter.
3. The study explored the barriers that parents face when caring for their children with disabilities. Finance was the most common barrier that keep parents from doing their best in taking care of their children. However, parents have different strategies that they use, and they facilitate for them to ensure they care for their children.

The objectives of the study were to;

1. Explore the parent-child relationship;
2. Explore the strategies used by parents to ensure the health and well-being of their children living with a disability;
3. Explore the barriers of health and well-being experienced by parents in caring for their children living with a disability;
4. Explore how parents utilize their capabilities of (bodily health, emotions, affiliation and control of their environment) to ensure the health and well-being of their children with disabilities.

The study explored how parents use their capabilities (specifically their emotion, affiliation, bodily health and control over the environment capabilities) to ensure the health and well-being of their children.

6.2 Summary of the Findings

6.2.1 Theme 1: Capabilities of Emotions

This theme answered one of the research objectives of the study which was to explore parents' capabilities of emotions. In this study, 7 out of 12 parents reported that they express their emotions verbally for the other person to know that something has made them feel a certain way (whether good or bad). Expression of emotions is one of the three emotion regulation strategies that people use to control their emotions. However, culture has an important influence on the experience, expression, and labelling of emotions. It puts pressure on how people regulate and on when, and how, they should, or should not, express their emotions (Fernández, Carrera, Sánchez Fernández, Paez & Candia, 2000). It also influences the appropriateness of emotional expression (Fernández, Carrera, Sánchez Fernández, Paez & Candia, 2000).

One parent reported that sometimes she can’t express herself to her husband because she feels like he will not understand her and this is rooted in the beliefs that men, unlike women, show less emotions. Other parents reported either expressing their emotions non-verbally or not at all. Parents also reported that they deal with their emotions differently. They mentioned that they deal with their emotions by crying, praying, or talking to a person they trust. The parents also highlighted that sometimes they do not experience unpleasant emotions because they are raising children with disabilities, but rather because of the environment in which they are raising their children.

Furthermore, most parents reported to be happy with the love and support they get from people around them. This means that they are able to have attachments with people outside of themselves. Moreover, their use of religion and spirituality as means to cope with emotional distress shows a level of attachment, to some higher power. Having capabilities of emotions is also associated with higher self-esteem, better quality of life, positive psychological adjustment, and spiritual and stress-related growth (Wachholtz & Pearce, 2009). According to Nussbaum (2003), emotions are not just the driving force that powers the psychological mechanism of individuals, but they are a highly complex, and messy, part of the individual. Therefore, emotional well-being should be promoted in political culture and policies should focus on the emotional well-being of individuals as without emotional development, a part of our reasoning capacity as individuals will be missing (Nussbaum, 2003).

6.2.2 Theme 2: Capabilities of Affiliation

This theme answered one of the research objectives of the study which was to explore parent’s capabilities of affiliation. Affiliation is the act of interacting and associating with one or more people (Leary, 2010). It is often important because people affiliate to get emotional support and obtain positive stimulation (Leary, 2010). Participants in the study were asked about their friendships as parents who are raising children with disabilities. Fifty-eight percent (58%) of the parents interviewed reported that they do not have problems with making friends. However, the other 42% of parents noted that they do not find it hard to make friendships, but they just do not have people they consider to be friends as they talk to anyone around them. Their reasons for not having friendships were either that they were too busy to have time for friends, they prefer to spend most of their time at home, they are not outspoken, or they just prefer not to put a tag on people and call them friends.

Parents of children with disabilities tend to have fewer friends because of the attitudes some friends may have towards their children with disabilities (Thwala *et al.*, 2015). However, in this study they highlighted that even though they do not have people they call 'friends', they are still social people. While the participants did not mention anything about having difficulties in making friends because of their children's conditions, one did mention that sometimes it becomes difficult because a person will ask about the child or not understand the child's condition. This highlighted that parents have the opportunity to utilize their freedom and have friends, but they choose not to. They are able maintain relationships with their neighbours that they appreciate and respect, however, in terms of friendships, most parents have capabilities of affiliation but do not utilize them.

With regard to respect, participants' responses were mostly positive with only a few having negative reports. Participants respect the people around them and appreciate them for the things they have done for them and the way they have treated them. However, one participant mentioned how she once had a fight with some woman in her community because she was swearing at her child. This theme highlighted that, in some communities, having a child with a disability is still seen as a bad thing and something people can use against you. It shows that, in some communities, parents do not enjoy the freedom and dignity they deserve because they are raising children with disabilities. All the negative attitudes towards people with a disability are misconceptions that come from a lack of proper understanding of disabilities and how they affect the functioning of the person with the disability (Thwala *et al.*, 2015). People in communities still need to be made aware of disabilities to be able to understand them and to respect and support parents and children with disabilities.

6.2.3 Theme 3: Capabilities of Control Over One's Environment

This theme answered the research objective to explore parents' capabilities of control over the environment. Control over the environment is one's ability to have control over the things that have an influence on the individual, including political decisions and material things. According to Nussbaum's central human capabilities, citizens should have the ability to participate effectively in political decisions that govern their lives. Some participants reported that they do not participate in community activities because of time, reporting that they need to take care of their children and complete household chores. One parent reported that she would like to be more involved in the community, however, she also needs to consider her need to be at home most of the time to take care of her child with cerebral palsy. Another parent mentioned that she sometimes cannot go to community meetings because she does not have someone to look after her son when she wants to attend the meetings. One mentioned that she feels like she does not fit into community activities like meetings. Parents showed that they would like to be more involved in things that affect them in the community but the responsibilities they have at home do not allow them.

Some parents mentioned that they do get involved in community activities like meetings. However, one could tell that as much as they get involved, they do not attend regularly and they attend if the meetings are not going to take a lot of their time. The parents did not mention participating in any big community roles, besides voting during election time and attending meetings, which some of parents did not attend. However, one parent mentioned that she was once appointed for a role in the community but she could not take it because of her responsibility to take care of her children.

Regarding material things, only 5 out of the 12 parents own houses while others are staying in shacks. The parents that are staying in shacks mentioned how they do not like staying in them and they spoke about how challenging it is to raise their children in those environments. Moreover, another parent mentioned that living in her shack is more stressful than actually taking care of her child. Parents are also faced with unemployment as they are unable to go to work because they want to be available to their children when they need them. One parent mentioned that she cannot work because in some jobs she would not be allowed to attend to emergencies that concern her child. The issue of unemployment affects their finances and also the conditions they, and their children, live under. This theme showed that the parents do not have the capabilities of control over their environment.

Nussbaum's list of central human capabilities states that people should have the right to seek employment on an equal basis with others and participate in political choices that govern their lives (Nussbaum, 2001, 2007, 1997). This study showed that the parents do have the right of employment, but employment does not allow them to have functionings that are valuable to them such as being available to their children. The capabilities are there, however, they are unable to participate in them because they are not suitable for their lives as parents of children with disabilities. Not having the freedom to have control over things that influence their lives exposes parents to poverty (Curtis & Cosgrove, 2017).

6.2.4 Theme 4: Capabilities of Bodily Health

According to Nussbaum (2003), bodily health focuses on 'good health' and she addresses the importance of nutrition, housing, and reproduction health. Bodily health is not just the absence of diseases. Participants were asked questions that aimed to explore their health, the choices they make about what they eat, and the conditions they live under. Most participants believed that they are healthy and while they acknowledged that sometimes they get sick with fevers and colds, and go to the clinic, they noted that this is not something that means they are unhealthy.

Some participants only recognised physical health as an area to be associated with health. However, two participants mentioned that they are not healthy because they believe they are not emotionally healthy. One mentioned that she sometimes finds it hard to wake up because of the emotional stuff she goes through and that she sometimes has to force herself to do some things at home. The other parent reported that taking care of her kids has affected her over time. Both participants acknowledged the mental health component of the WHO (2011) definition of health and noted that even when they are physically healthy, their mental health is affected by their emotions and their responsibilities as parents raising a child with disability.

Parents mentioned that they try to get their families to eat healthy, however, with the little money they have most of them mentioned that they only buy essential things, after getting those staples they can then add a few of healthy food. Money was what hindered most of the parents from getting healthier food for their families. Furthermore, participants lack capabilities of bodily health due to financial struggles and lack of formal support services for their mental health. This theme answered one of the objectives of the study which was to explore parents' capabilities of bodily health. This theme highlighted that there is still work to be done in both teaching people to acknowledge mental health and ensuring that people eat food for nourishment, not just survival, and that they have proper housing.

6.2.5 Theme 5: The Kind of Relationship Parents Have with Their Children

This theme answered one of the research objectives to explore the kind of relationship parents have with their children with disabilities. Parents in this study were asked about the nature of their relationships with their children with disabilities and most participants reported that they have good relationships with their children. A parent-child relationship is the quality of the emotional connection between child and parents (mother and father or significant parental figure) and the degree to which this connection is mutual and sustained over time (Lezin, Rolleri, Bean, & Taylor, 2004). Only one participant reported that she is experiencing problems in her relationship with her son. Regardless of the challenges parents face with raising children with disabilities, most parents showed that they have great love for their children. They still play and show love to their children regardless of their children’s condition. Parents showed that they have some level of connection with their children.

Availability of parents to their children seemed to an influence on the kind of relationship they have with their children as it has resulted in the children and parents having some connection and understanding. The parents in this study did not mention if they raise their children with disabilities any different from the ones that do not have disability. They referred to their children as one, and only when the interviewer specified to get an answer to a question based on the child with disability, did they differentiate between their children. This could mean that they do not treat their children differently, but it must be noted that this was not explored. This theme highlighted that parents raising children with disabilities are not parenting in a different way to parents raising typical developing children.

6.2.6 Theme 6: Strategies and Facilitators Used to Ensure the Health and Well-being of Their Children

This theme answered one of the research's questions and objectives, to explore the strategies used by parents to ensure the health and well-being of children with disabilities. Encouragement is one of the strategies used by parents to ensure the health and well-being of their children with disability. Parents encourage their children, seek encouragements and also encourage themselves to be strong. Most parents find themselves having to continuously encourage their children, comfort and assure them of their love. Parents in the study mention that they continually encourage their children when people say bad things to them, and assure them of their love regardless of what other people say. One parent mentioned that she has to keep encouraging herself to accept her child in order to be a good parent to her child. This shows that parents do not only have to encourage their children, but also have to encourage themselves to be good parents to their children. Some parents stated that they pray and go to church to receive the encouragement and strength they need to be raise their children.

Availability is another strategy that most parents use to ensure the health and well-being of their children. Parents' availability to their children is important in ensuring the health and well-being of their children (Woodgate, Edwards, Ripat, Borton & Rempel, 2015). Parents in the study mentioned that they need to be home most of the time to be with the children. Some parents even decided to not have jobs so that they can always be available to look after their children. Availability is not only their strategy in terms of looking out for their children's health, but it also includes other things like being there to make sure their children are fed, bathed, and assisted when they need some assistance (like going to the bathroom for those children who use wheelchairs).

The last strategy participants used is support. According to Vanegas and Abdelrahim (2016), parents also require emotional/social support, educational support and instrumental support. Parents get support grants from the government in the form of a grant, disability grant or care dependency grant. Those who receive the grant report getting R1, 700 per month. The parents mention that the grant helps them a lot in taking care of their children, as it helps them do basic things like buy food, clothes, and pay rent. Others use some of this money to pay for their children's school transportation. Support is not only they monetary support they get from the government but also the social support they get from their neighbours. Wojtas, Oskędra, Cepuch, and Świderska (2014) found the existence of a correlation between the level of social support received by parents and how they cope with the challenges of raising children with illnesses. The only emotional or social support parents gets is from their families and neighbours and this showed that parents are depended on informal forms of support.

This theme highlighted that these strategies should be seen as a starting point to explore what parents are currently doing and where they can be helped in order to strengthen their capabilities to produce functionings that they value. If being constantly available to their children is important to them then that should be seen as a priority when providing resources to help them. Looking at parents' strategies provides room to not assume what parents need but to look at the capabilities they currently hold and to be able to know what is important to them. More research is needed to investigate the kind of functionings parents raising children with disabilities value, before imposing what we assume is important to them.

6.2.7 Theme 7: Barriers That Prevent Parents from Ensuring the Health and Well-being of Their Children

Parents on the study were asked to mention the things that act as a barrier between them and their ability to ensure the health and well-being of their children. The question was asked to explore what they perceived as a blocking barrier from being entirely capable from taking care of their children. Financial problems were the most common issue mentioned by the participants. Finances have an influence on the food they buy for their children as well as their ability to transport them to hospital for their hospital visits. It also influences the condition of most of their houses/shacks.

McNally and Mannan (2013) mention that parents raising children with disabilities struggle financially because of lack of employment. Half of the participants in this study were unemployed due to their responsibility to their children and their desire to always be available for their children as they do not have someone else to look after them. The issue of finances goes back to the topic employment which further goes back to control over the environment capabilities. This highlights the lack of capabilities of control over the environment in Nussbaum's list of capabilities which states that people should have the right to seek employment on an equal basis with others (Nussbaum, 2001, 2007, 1997). The parents do have the right of employment; however, employment does not allow them to have functionings that are valuable to them such being available to their children. This theme answered one of the research questions and research objectives which was to explore the barriers that prevent parents from ensuring the health and well-being of their children. It highlighted the need to look into work policies to accommodate everyone, and to give parents raising children with disabilities the capabilities to be able to work flexible hours to gain money that will help their functioning and be available for their children. Parents raising children with disabilities need to have different employment policies that will allow them to juggle taking care of their children and having the means to gain an income by getting a fair chance in being employed without having to sacrifice one of the two.

6.3 Limitations of the Study

Although the study was structured, and constructed, well, there were limitations that were identified that might have had a direct or indirect influence on the outcome of the study. This study was conducted in the Western Cape and used parents from the city of Cape Town only. Cape Town is an urban area and therefore the study did not include participants from rural areas which would have made the study more inclusive of different geographical areas with different resources and opportunities. Participants of this study were mostly female, which limited the study in getting a male perspective on raising children with disabilities. This study also did not include participants with diverse cultures. This could have enhanced the perspectives and experiences much more. Another limitation to the study was that the researcher could have specified the age limit of the children. Parents with older children (such as the parent with a 24-year-old) had to recall old experiences because they do not encounter many challenges with their children who are now older and more capable of taking care of themselves.

6.4 Recommendations

The following recommendations are made based on the findings of this study. They are made for policy makers, parents raising children with disabilities, practitioners working with parents and children with disabilities, and for future research to improve the health and well-being of children with disabilities.

6.4.1 Based on the findings of this study, parents use three main strategies to ensure the health and well-being of their children. They encourage themselves, and their children, to always be positive, ensure that they are constantly available for their children, which to some parents means not working, and lastly utilizing the support they get, in terms of the grant and support from friends and relatives. Recommendations for parents raising children with disabilities include:

- Parents should focus more on their capabilities and on how they deal with their emotions. They should try to always voice-out when not feeling well and adopt strategies to deal with their emotion and not avoid them. Talk to friends and family about their emotions or seek professional help where necessary.
- They should create affiliations with people they trust and know that they can rely on for support.

- To those who are not working, they should look for ways to make an income from working from home, like selling things. This will enable them to have money to supplement the grant they receive to buy food and help with other expenses.

- Parents should apply for RDP houses under the child with a disability. In South Africa people with disabilities are given priority in receiving the houses that are adapted to their needs. Parents should seek that information and apply.

6.4.2 The government and policy makers are already catering for people with disabilities in terms of giving them support (grants and programmes), however, parents are still faced with the same challenges, financial struggles, and emotional distress.

Recommendations for policy makers/the government include:

- The government should ensure that they keep their promise of prioritising people with disabilities in giving houses that are catered for their needs. They should also make the process easy and less complicated for the parents to apply. As one parent in the study mentions how difficult the process has been for her.

- They must provide programmes to parents raising children with disabilities that aim to empower and provide support to the parents. These programmes should help them to look at their lives more holistically (mental health, physical health, emotional and financially).

- Create awareness in communities about accepting and respecting people with disabilities. To deal with the stigma and discrimination against people with disabilities.

- The government should create more working spaces that cater for parents who cannot work long hours because they need to take care of their children. Parents should also be allowed to attend to any emergencies without fear of losing the job.

- Create centres/aftercare for children with disabilities for parents that work long hours.

6.4.3 Recommendations for Practitioners (Social worker and Psychologist)

- Create interventions that aim to empower and support parents to look at their lives holistically. This includes not only looking at their mental/emotional health but also at ways to develop financial freedom and independency.
- Teach parents ways to deal with, and express, their emotions instead of avoiding them.
- Help parents through processes like housing applications and teach them about the resources that are available for them, but that they might lack information about.

6.4.4 Recommendations for Future Research on Parents Raising Children with Disabilities

Studies that focus on a larger scale of parents from different backgrounds and ethnic group are needed to give more insightful findings. There should also be more studies that focus on what can be done to help parents with the challenges they encounter when raising children with disabilities are recommended. Finally, a study that focuses on other capabilities of parents, and how to enhance them, is recommended.

6.5 Conclusion

According to the findings, the research questions were answered and the aims, as well as the objectives of the study, were met satisfactorily. The findings established the strategies parent use to ensure the health and well-being of their children which include being constantly available to attend to their children’s need and encouraging their children and themselves when necessary to accept their children with the condition. Using the support, they get from the people close to them and using well the grant for their necessities.

The findings also established the positive parent-child relationships that exist between parents and their children. The study also established that finance is the most common factor that prevents parents from ensuring the health and well-being of their children to the best of their ability. Lastly, the study established that parents need to enhance their capabilities on all four capabilities. From the results presented, it is evident that parents do try their best to ensure the health and well-being of their children, however, they are not presented with enough capabilities to achieve valued functionings, hence the challenges they still facing. Therefore, a focus should move from looking at the challenges/experiences they encounter to a focus on what capabilities they need in order to achieve a life that is worthy for their child.

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APPENDICES

Appendix A

Interview schedule

Date: Time:

Please ask the following demographics questions at start of interview:

Huis taal/Home Language/ulwimi lwasekhaya:

Ouderdom/Age/iminyaka:

Ras/Race/Uhlanga:

Nomer van Kinders/No. of kids/imani labantwana:

Grants: Child or other:

Hoogeste graad/Highest grade/ standard passed/phele kubani esikolweni:

Indiensneming/Employment/ingqesho:

Bunjani ubudlelwane bakho nomtwana wakho?

How is the relationship between you and your child?

Wenza ntoni ukuqinisekisa ukuba umntwana wakho usempilweni ntsuku zonke?

What do you do daily to ensure health and well-being of your child?

Zintoni ezikwenza ukuba kubenzima ukuba uqinisekise ukuba umntwana wakho usempilweni?

What barriers hinder you in ensuring your child's health and well-being?

Zintoni ezincedisana nawe ukuba uqinisekise ukuba umntwana wakho usempilweni?

What helps you to facilitate well to ensure your child's health and well-being?

<u>Emosie/Emotion/imizwa</u>

1. Hoe maklik/moeilik vind jy it is om liefde, sorg en ondersteuning van jou gesin en vriende te geniet?

How easy/difficult do you find it to enjoy the love, care and support of your family and friends?

Kulula okanye kunzima kangakanani ukonwabela uthando, inkathalo nenxaso yosapho lwakho kunye nabahlobo?

2. Hoe druk jou emosies uit? (Ondersoek: Voel jy soms dat jy nie emosies kan uitdruk nie, Hoekom?)

How do you express emotions? (Probe: Do you ever feel that you can't express your emotion and why?)

Uyiveza kanjani imvakalelo yakho? (: ukhe uzive ingathi awukwazi ukuveza imvakalelo yakho, kwaye ngoba kutheni?)

3. Hoe maklik/moeilik vind jy it is om gevoelings van liefde, hartseer, verlange, dankbaarheid en woede uit te druk? (kan jy asseblief byvoorbeelde gee?)

How easy/difficult do you find it to express feelings of love, grief, longing, gratitude and ager? (can you please give examples?

Kunzima/kululala kangakanani ukuveza imvakalelo zakho malunga nothando, ukwaneliseka, ukucaphuka, ukurhalela kunye nonxunguphalo? (ungandinika imizekelo?)

4. Wat is die mees algemene emosies wat jy op 'n daaglikse basis ervaar? (Ondersoek: hoe hanteer jy dit?)

What is the most common emotion you on a daily basis? (Probe: How do you deal with it)

Yeyiphi eyona mvakalelo ohlala unayo ntsuku zonke? (…Uhlangabezana njani nayo)

5. Hoe maklik/moeilik vind jy it is om vriende te maak?

How easy/difficult do you find it to make friends?

Kulula okanye kunzima kanjani ukwenza abahlobo?

6. Hoe gereeld het jy slaap verloor oor its wat jy bekomeerd is of jou plaa? (soo in die laste vier weeke)

How often have you lost sleep over worrying about something? (in the past 4 weeks)

Kukangakanani ulahlekelwa bubuthongo ngenxa yokukhathazeka ngento? (kwezi veki zine zidlulileyo)

7. In die laste 4 weeke, hoe gereeld het jy gevoel dat jy is onder konstante druk (pressure) (hoekom)

In the past 4 weeks, how often have you felt under constant strain? (why?)

Kwezi veki zine zidlulileyo, kukangakanani apho uva ingathi uphantsi koxinzelelo? (ngoba kutheni usiva njalo)

8. Hoe verstaan jou kinders wat emosies is? (Ondersoek: hoe se jy vir jou kinders hoe om hulle emosies uit te druk?)

How do your child/ren understand what emotion is? (Probe: How do you tell your children to express their emotions?

Umntwana wakho uyayiqonda ukuba yinto imvakalelo? (umxelala kanjani umntwana wakho ukuba makayiveze indlela aziva ngayo?)

<u>Affiliasie/Affiliation/uvisiswano nabanye abantu</u>

1. As jy rondom jou kyk, hoe voel jy teenoor hulle? (Onderdoek: mense na an jou? Mense nie na aan jou nie?) Wat dink jy van hulle waarde in jou lewe? Voel jy dat jy hulle ‘respect’ en waardeer? (hoekom?)

If you look at others around you, how do you feel towards them? (Probe: people you are close to? And people you are not close to?) What do you think of their value in your life? Do you feel that you respect and appreciate them? (why?)

Xa ujonga kwabanje abantu abakungqungileyo, uzifanjani kubo? (Abantu abakufutshane kuwe?) Kunye nabantu abangekho kufutshane kuwe?) Ucinga ntoni nokubaluleka kwabo ebomini bakho? Uziva ubahlonipha kwaye ubakhathalele? (Kutheni usitsho njalo)

2. Hoe betoon jy omgee vir ander? (Ondersoek: en mense wat jy nie ken nie?)

How do you show concern to others? (Probe: and people you don’t know?)

Uveza kanjani ukuba abakhathalele abanye abantu? (Ebantwini ongabaziyo wenza njani?)

3. Hoe leer jy jou kinders om om te gee vir ander? (Ondersoek: byvoorbeeld, as iemand beroof word of seerkry, wat sê vir jou kinders omtrent die ander persoon se situasie? Verskaf asseblief ŉ voorbeeld)

How do you teach your children to show concern to other? (Probe: for example, if someone is not feeling well or is in trouble how would they show concern? Please provide an example)

Ubafundisa kanjani abantwana bakho ukuveza ukukhathalela abanye abantu? (Umzekelo, ukuba umntu ukaphilanga okanye omnye umntu usengxakini)

4. Wat sal jy doen as jy uitvind in jou woonbuurt dat die enigste een wat werk in die huis, hul werk verloor het? (Ondersoek: wat jou eerste reaksie wees? Wat sal jy doen?

What would you do if you found out that your neighbourhood, who is the only one working in the home, lost their job? (Probe: What would your first response be? What would you do?)

Ungenza ntoni ukuba ungafumanisa ukuba umakhelwana wakho, ongoyena mntu uphangelayo emzini ukuba ulahlekelwe ngumsebenzi? (Ingayintoni eyona nto yokuqala ongayithetha? Ungenzani)

5 Hoe gereeld ontmoet jy saam vriender of familie/gesin? (hoekom?)

How often to you meet up with friends or family? (why?)

Uhlangana amaxesha amengakanani nabahlobo kunye nosapho lwakho? (Kutheni kunjalo)

5. Het jy enige vorm van diskriminasie ervaar? (Ondersoek: Waar en hoekom?)

Have you ever experienced any form of discrimination? (Probe: When and how?)

Inside or outside any worksplace, community, household in any form because of your:

Race, sexual orientation, gender, religion, age, health or disability?

Wakhe wafumana ucalu-calulo noba lunjani (Kwakunini kwaye kanjani)

Control over one's Environment

1. How active are you in your community?

Ingakanani inxaxheba uyidlalayo kwindawo ohlala kuyo?

2. How involved are in you politics? (Probe: do you vote? Why?)

Ubandakanyeka kangakanani kwezopolitiko? (Uyavota na? Ngoba kutheni?)

3. Do you have discussions with your children about politics and making decisions about politics?

Ubanazo na ingxoxo nomntwana wakho malunga nezopolitiko kunye nokwenza izigqibo ngezopolitiko

4. Do you own land or property/ a house?

Unawo na umhlaba/okanye indlu yakho?

Depending on employment in demographics section:

If unemployed: Do you actively look for work? (Probe: what opportunities are available?)

If employed: How would you describe your relationship with co-workers?

Ask for everyone: How helpful is the grant money that you receive?

Xhomekeke uluqasheweni kwincukacha :

Ukuba awuqheshwanga: Uwufuna ngamandla umsebenzi? (Ngawaphi amathuba avelayo?

Ukuba uqashiwe: Ungabuchaza njani ubudlelwana bakho nabantu ophangela nabo?

Buza wonke umntu: Iluncedo kangakanani imali yesibonelelo sikarhulumente oyifumanayo?

Bodily Health

a) Life-style and Health status

1. Do you think that you are healthy and why?

Ucinga ukuba usempilweni kwaye kutheni ucinga njalo?

2. How healthy do you think your children are and why?

Ucinga ukuba basempilweni abantwana bakho kwaye kutheni ucinga njalo?

b) Nourishment

1. Do you think the food that you eat is healthy and why?

Ucinga ukuba ukutya okutyayo kusempilweni kwaye kutheni ucinga njalo?

2. What do you do to make sure that your child/ren eat healthy?

Wenzani ukuqinisekisa ukuba umntwana wakho utya ukutya okusempilweni?

5. Describe the choices you have in what you eat and do you think these choices are healthy?

Chaza isigqibo ozithathayo malunga nento oyityayo kwaye ucinga ukuba ezo zigqibo zisempilweni?

c) Adequate Shelter

1. Where are you currently living? (Probe: Do you have your own house or are you living with or on someone's property?)

Njengangoku uhlala phi? (Unendao yakho yokuhlala okanye uhlala nomntu okanye yindawo yomnye umntu?)

If living on someone else's property:

1. Do you see yourself owning your own house one day?

Uyazibona uneyakho indlu ngenye imini?

2. Do you think that your children may own a house one day? Or yes or no why?

Ucinga ukuba umntwana wakho anganayo eyakhe indawo yokuhlala ngenye imini? Ewe okanye hayi, ngoba kutheni?

__General__

1. Bunjani ubudlelwane bakho nomtwana wakho?

How is the relationship between you and your child?

2. Wenza ntoni ukuqinisekisa ukuba umntwana wakho usempilweni ntsuku zonke?

What do you do daily to ensure health and well-being of your child?

3. Zintoni ezikwenza ukuba kubenzima ukuba uqinisekise ukuba umntwana wakho usempilweni ?

What barriers hinder you in ensuring your child's health and well-being?

4. Zintoni ezincedisana nawe ukuba uqinisekise ukuba umntwana wakho usempilweni?

What helps you to facilitate well to ensure your child's health and well-being?

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Appendix B IPHEPHA-MVUME

ISAHLUKO SOPHANDO: Ukubona amaqhinga wabazali ukuqhinisekisa ezempilo zabantwana babo abakhubazekileyo

Oluphando ndilucaciselwe ngolwimi endiluvayo nendiluqondayo. Imibuzo endithendanayo ngesisifundo iphenduliwe. Ndinolwazi malunga nokuzibandakanya kwam kwesisifundo, ndiyavuma ukuzibandakanya kwesisifundo ngentando yam nangokuzikhethela. Ndiyaqonda ukuba ubuni bam ukuzokwaziwamntu. Ndiyazi ukuba ndicinga ngongabiyinxalenye yesisifundo ndinelungelo lokwenza oko. Ndingashenxa kwesisifundo ndingakhange ndizicacise, ngaphandle koloyiko lweziphumo ezimbi. Nidyavuma ukuba oludliwano-ndlebe lushicilelwe.

Igama lomntu othatha inxaxheba………………………..

Isayini yomntu othatha inxaxheba ……………………………….

Umhla………………………

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Appendix C Consent form

Title of Research Project: Strategies of parents to ensure the health and well-being of their children with disabilities: A human capabilities approach

The study has been described to me in a 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 understand that there will be an interview which will be recorded.**

.... I agree to be audio recorded
.... I do not agree to be audio recorded

Participant's name………………………..

Participant's signature……………………………….

Date………………………

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Appendix D

INFORMATION SHEET FOR ALL PARTICIPANTS

Project Title: Strategies of parents to ensure the health and well-being of their children with disabilities: A human capabilities approach

What is this study about?

This study is about the strategies used by parents to ensure health and well-being of their children with disabilities, within capability framework.

This is a research project being conducted by Abulele Hashe the University of the Western Cape. I am inviting you to voluntarily participate in this research project to provide me your understanding of the strategies you as a parent use to ensure the health and well-being of your child/ren with disability. The purpose of this research project is to explore strategies used by parents to ensure health and well-being of their children with disabilities using human capabilities as a framework.

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

You will be asked to participate in an interview. The interview questions will ask you about the study you are participating in, questions about the disability of your child, your emotions, control over your environment, your health and affiliation. Interview will take place in a private space, and it will take 30minutes to an hour, while the questionnaire will be completed in 30minutes. **The interview would need to be recorded but it will only be done with your permission.**

Would my participation in this study be kept confidential?

I undertake to protect your confidentiality and to protect it, the information you provide will be totally private; no names will be used so there are no way you can be identified for participating in this study. Your information will be anonymous and treated confidentially. This will be done by not adding your name in the report but rather using a pseudonym or a code. If I write an article about this research, your identity will be protected to the maximum extent possible. The data collected will be kept in a locked cabinet and only the interviewer and the research supervisor will have access to this information. The research findings will not include any personal details. After completion of the project your information will be disposed. In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities' information that comes to my attention concerning neglect or potential harm to you or others. In this event, l will inform you that l have to break confidentiality to fulfil legal responsibility to report to the designated authorities

What are the risks of this research?

Any research has risks. If you feel challenged in any way by the questions being asked, we will refer you for the necessary support or you may choose not to participate or withdraw at any time during the data collection process. If at any time there is disclosure of any incidents of risks or harm during the research process, we are legally compelled to report the information.

What are the benefits of this research?

I am not designed to help you personally however; the results of the study may help, as there will be recommendations on what can be used to help parents ensure health and well-being of their children. The results of this study will provide insight for other parents about how they can ensure the health and well-being of their children. This information is also important for government so that they can implement programmes which can families and hopefully empower parents about the strategies they used and capabilities to reduce child neglect and maltreatment, creating a better world, society and communities for children.

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 in the study. If you decide to participate in this research study, 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 penalised or lose any benefits to which you otherwise qualify.

Is any assistance available if I am negatively affected by participating in this study?

Every effort has been taken to protect you from any harm in this study. If however, you may feel affected you can be referred to your nearest community resource for assistance.

What if I have questions?

This research is being conducted by Abulele Hashe, at the University of the Western Cape. 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 Roman at nroman@uwc.ac.za or Prof Mlenzana at nmlenzana@uwc.ac.za

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Appendix E

ULWAZI MALUNGA NOPHANDO

ISIHLOKO SOPHANDO: Ukubona amaqhinga wabazali ukuqhinisekisa ezempilo zabantwana babo abakhubazekileyo

Lungantoni oluphando?

Oluphando lwenziwa ngu Abulele Hashe ongumfundi kwi Dyunivesithi yase Ntshona-Koloni. Uyamenywa ukuba uthathe inxaxheba koluphando ngoba unolwazi malunga namaqhinga asetyenziswa ngabazali ukujongana nempilo yabantwana babo abakhubazekileyo. Injongo yoluphando kujonga ukuba abazali benza waphi amaqhinga ukuhlala bejongene nempilo kuye nokuphila kontwana okhubazekileyo.

Kulindeleke ntoni xakunokuthi ndivume uthatha inxaxheba koluphando?

Uyakucelwa ukuba ube yixalenye yodliwano-ndlebe oluzothi lwenziwe malunga namaqhinga wabazali ukuqinisekisa impilo yabantwana babo abakhubazekileyo kunye nezakhono zabo. Oluphando luzakubuza malunga nomtwana wakho okhubazekileyo, ubudlelwane bakho nabanye abantu, ukuba unamandla angakanani kwizinto ezikungqungileyo kunye nemizwa yakho. Udliwano-ndlebe luzothatha imizuzu engamashumi amathathu ukuya kwiyure enye. Uzacelwa ukuba uRikhodishwe kwaye uvumelekile ukuba ungavumi xa uthanda.

Ingaba ukhuseleko lwam luqinisekisiwe kweisisifundo?

Umphandi uzozama ukukhusela ubuni kunye nobume begalelo lakho. Ukuqinisekisa ukuba igalelo lakho likhuselekile; umphandi akayi kusebenzisa igama lakho ngexesha lo dliwano-ndlebe naxa ebhala ngodliwano-ndlebe. Idatha iya kugcinwa kwikhabhinethi ekhethiweyo kunye nakwi khompyutha apho kuphela umphandi kunye nabaphathi bayo abaza kufikelela kuyo. Ngokuhambelana neemfuno zomthetho kunye / okanye imigangatho yezobugcisa, siya kubhengeza olulwazi kubantu abafanelekileyo kunye / okanye igunya lokufumana ulwazi malunga nokuxhaphazwa kwabantwana okanye ukunganakwa okanye ukulimala wena okanye abanye. Kulo mcimbi, siya kukuxelela ukuba kufuneka sidize imfihlo ukuze sizalise uxanduva lwethu lomthetho ukunika ingxelo kumagosa atyunjiwe. Olu phando luya kusebenzisa amaqela a kwaye ubungakanani bokuba izazisi zakho ziya kuhlala ziyimfihlo zixhomekeke kubathathi-nxaxheba kwiqela elijolise kuyo ukugcina imfihlo.

Zeziphi iingozi zoluphando?

Kungakhona ubungozi kolu phando. Uzokunikisa ngolwazi olunokuthi lube negalelo kuwe kumvakalelo okanye oko kunokuchaphazela indlela oziqonda ngayo ezi zinto. Zonke iintsebenziswano zabantu kunye nokuthetha ngabanye abantu zinobungozi. Umphandi uya kunciphisa ingozi kwaye enze ngokukhawuleza ukuncedisa ukuba uye weva uxinizelelo ngokwe ngqondo okanye enye indlela ngexesha lokuthatha inxaxheba koluphando. Xa kuyimfuneko, ukuhanjiswa okufanelekileyo kuya kwenziwa kwicandelo elifanelekileyo lochwepheshe ukuze uncediswe olunye okanye uncedo. Ukunikezelwa kweenkonzo kuwe, intsapho yakho okanye umntu ogula ngengqondo akuyi kuchaphazeleka ngokuthi uthathe inxaxheba koluphando.

Zeziphi iinzuzo zoluphando?

Oluphando alwenzelwanga ukunceda wena, kodwa iziphumo zinokukunceda umphandi afunde kungakumbi ngamaqhinga anziwa ngabazali ukuqinisekisa impilo yabantwana abakhubazekileyo. Siyathemba ukuba, kwixa elizayo, abanye abantu banokuzuza kolu phando ngokuthi kuhlelwe indlela ezingcono abazali abangaqinisekisa ngazo impilo yabantwana abakhubazekileyo ngokuthi bafundiswe ngezakhono abanokuzisebenzisa.

Ngaba kufuneka ndibe kuloluphando kwaye ndivumelekile ukuyeka ukuthatha inxaxheba nanini na?

Ukuthatha inxaxheba kwakho koluphando kungokuzithandela, ungakhetha ungathathi nxaxheba. Ukuba uzithandele ukuthatha inxaxheba ungayeka naxa uzisola sele uvumile. Ukunobangaba ukhetha ukungabiyinxalenye yesisifundo okanye uyeke sele ugaphakathi akuzobakho ziphumo zimbi, awuzokohlwaywa.

Ukuba ndinemibuzo?

Oluphando lwenziwa nguAbulele Hashe ofunda kwi Candelo lweze Ntlalo-ntle kwi Dyunivesithu yase Ntshona-Koloni. Ukuba unemibuzo malunga noluphando, nceda uqhagamishelane nabaphathi uProf Roman kule imeyile nroman@uwc.ac.za okanye uProf Mlenzana kule imeyile nmlenzana@uwc.ac.za

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KwiSebe lezeNtlalontle

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UMlawuli weCandelo loLuntu kunye neSayensi yezeMpilo
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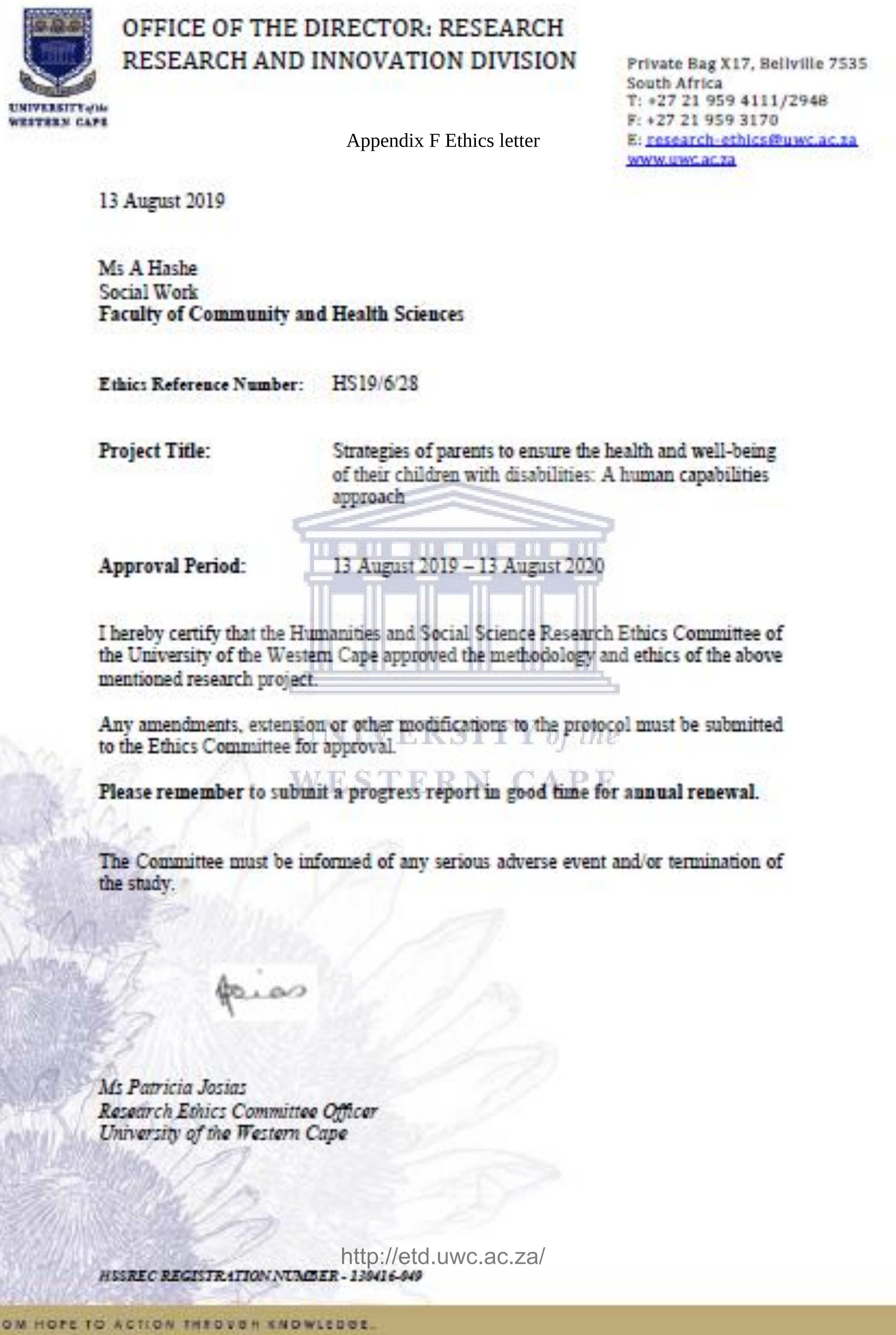
Appendix F Ethics letter



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13 August 2019

Ms A Hashe
Social Work
Faculty of Community and Health Sciences

Ethics Reference Number: HS19/6/28

Project Title: Strategies of parents to ensure the health and well-being of their children with disabilities: A human capabilities approach

Approval Period: 13 August 2019 – 13 August 2020

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

HSSREC REGISTRATION NUMBER - 130416-049

FROM HOPE TO ACTION THROUGH KNOWLEDGE.