

**AN EXPLORATION OF HUMAN CAPABILITIES OF PARENTS WITH
CHILDREN (0-8 YEARS) WITH DISABILITIES**

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**Full thesis submitted in fulfilment of the requirements for the Degree of
Masters in Child and Family Studies in the Centre for Interdisciplinary**

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Abstract

Parenting a child with a developmental disability has a significant impact on the lives of parents and/or caregivers as well as how the family functions. This is often due to the changes in life routines that are necessary to provide for childcare may therefore require certain capabilities of carers. There is limited research conducted on the human capabilities of parents with disabled children in South Africa. This study, therefore, explored the human capabilities of parents or caregivers with children younger than eight years with developmental disabilities. This study used a qualitative methodological approach to explore the experiences of the parents of children with developmental disabilities. The research sample included 11 participants comprising of mothers, fathers, grandparents, and legal carers of children with developmental disabilities. To explore parents experiences, Human capabilities theory was employed in the study. A qualitative approach was used in the study. Participants for the study were from disadvantaged communities in Cape Town. A semi-structured interview schedule was used to collect the data via face-to-face audio-recorded interviews. Collected data were analysed using thematic analysis. Previous research has indicated that bodily health and bodily integrity capabilities entail good health, adequate nutrition, adequate shelter, and the ability to move from place to place freely. However, the results show that the participants have challenges with taking their children for check-ups to the hospital since they did not have decent transport. The results also indicated that they are not adequately nourished and do not have adequate shelter since they were not employed. Therefore, this study concludes that there is a need to shift from remedial or welfare assistance and focus more on developmental practice which ensures the sustainability of interventions.

KEYWORDS: Capabilities, human capabilities, freedoms, opportunities, developmental disability parents, parenting, children with disabilities, family, capabilities approach

LIST OF ABBREVIATIONS

ASD:	Autism Spectrum Disorders
CA:	Capability Approach
CDG:	Care Dependency Grant
DSD:	Department of Social Development
DWCPD:	Department of Women, Children, and People with Disabilities
HRQOL:	Health-related quality of life
HSSREC:	Humanities and Social Science Research Ethics Committee
ICF:	International Classification of Functioning, Disability, and Health
ICF:	International Classification of Functioning, Disability, and Health
ID:	Intellectual Disabilities
NDP:	National Disability Policy
NIECDP:	National Integrated Early Childhood Development Policy
QOL:	Quality of life
UNCRC:	United Nations Convention on the Rights of the Children
UNCRPD:	United Nations Convention on the Rights of Persons with Disabilities
UNICEF:	United Nations Children's Fund
WHO:	World Health Organisation

DECLARATION STATEMENT

I, Lumka Magidigidi, declare that the Masters by Research thesis entitled “*An exploration of human capabilities of parents with children (0-8 years) with developmental disabilities*”. All sections of the dissertation and concepts developed by another author have been referenced, this thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree. Except where otherwise indicated, this thesis is my work.

Date: September 2021



Signed:

DEDICATION

I dedicate this thesis to my parents Eunice Nomzubanzi Magidigidi and my late father Mzimkulu Ephraim Magidgidi. Although my father is no longer in this world, their hopes and dreams are what put me here today. Camagu Mashiy'amahle.

ACKNOWLEDGEMENTS

Throughout the writing of this thesis, I have received a great deal of support and assistance.

I would first like to thank my supervisors, Professor Nicolette Roman, and Miss Inge Sonn, whose expertise helped put together my research questions and methodology. Your insightful feedback pushed me to improve my thinking and took my dissertation to a higher level.

The beginning of this journey in 2018 would not have been easy without the financial support of the NRF SARChI Scholarship offered by Professor N. Roman and Hillensberg Bursary offered by Professor Lorna Holtman from the University of Western Cape.

A special thanks to Miss Sisanda Holwana who introduced me to most of my participants, supported and helped me walk this journey. To all my participants, thank you for welcoming me with warm hands and sharing your stories with me. Lastly, I would like to thank my mother for her guidance and for providing a sympathetic ear when I needed it the most, and to all my UWC family who has contributed towards the completion of this journey.

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CHAPTER 1

INTRODUCTION OF THE STUDY

1.1 Background and Rationale

Researchers from the social and health sciences view disability from different positions and as such, they define the concept based on their unique perspectives and interactions (Goering, 2015). Disability is defined by the World Health Organisation (WHO), (2018) as a broader name for impairments, restrictions in activity, and participation. The link amongst individuals with a health condition such as Down syndrome, cerebral palsy, and depression as well as individual and environmental influences is termed as a disability. The term is used to refer to individual functioning, together with bodily impairment, physical impairment, intellectual impairment, poor mental health, and numerous types of chronic impairments. (Fredman, 2017) defining disability as individuals who have long-standing physical, mental, intellectual, or sensory deficiencies which, substantially impact several barriers and might limit their complete and actual involvement in society on an equal basis with others. In the study by Mitra (2017) disability is defined as a deprivation with regards to functioning(s) and/ or capability(s) amongst individuals who lack health. Individuals who lack health according to Mitra (2017) take account of impairments and health conditions, which are defined using World Health Organisation's (WHO's) definitions. An impairment is a problem in structure or bodily function as an important difference or shortfall (WHO 2018). For example, an impairment could be an important difference with regard to sight or vision. Disability classifies a particular kind of lack or difficulty that may be the target of policies (Mitra, 2017). Consequently, disability can affect not only those who are disabled but as well as those who are the primary caregivers. Since varying challenges such as unlimited resources and little or no assistance from the government, raising a child with a disability is difficult for most parents (Tigere & Makhubele, 2019). Parents are the most important people in the lives of young

children. Starting from birth, children will be learning and depending on mothers, fathers, or caregivers to safeguard or care for them and to guide them in a way that promotes their complete well-being (Gadsden, Ford & Breiner, 2016; National Integrated Early Childhood Development Policy, 2015). However, having a child with a disability might have an impact on the quality of child-caregiver relations (Beurkens et al., 2013). In addition, Malhotra, Khan, and Bhatia, (2012), revealed that that parent of children with several developmental disabilities encounter intensified stress, overstrain, and ignorant communities, fatigue, or tiredness. Mentioning that little or no consideration has been given to the health effects of parents or caregivers of children with developmental disabilities.

The health of a caregiver has a significant attribute that can influence the well-being of the child with disabilities that they care for (Geere et al., 2013). This is evident in a study by Muller-Kluits and Slabbert (2018) pointing out that caregivers prioritize the health of their children with disabilities and their other family members while risking their health. The authors also argued that parents' bodily health can also be affected by aspects such as deprived sleep, a larger risk of hypertension, pain, intensified headaches, and increased levels of infection. The parents of children with disabilities are also subject to poverty along with the shortage of required economic assistance; do not have reasonable contact to information required to offer suitable maintenance for their children; plus, have inadequate social assistance (DSD, DWCPD & United Nations International Children's Emergency Fund (UNICEF), 2012). These aspects might hold a negative outcome on the bodily and emotional health of mothers and fathers and their capability to fulfill their child's developmental requirements. Given that, many children with disabilities have elevated support needs because of disabling health conditions and impairments, and this dependency, adding to extra social and economic difficulties, might put a huge amount of stress on caregivers (WHO, 2012). This is evidence that poverty and inadequate access or unavailability to health care and assistive devices might have an impact on the bodily health of individuals who care for

children with disabilities (Geere et al., 2013). The World Health Organisation (WHO), 2012 pointed out that if children with developmental impairments and their families are not offered the required early involvement as well as assistance and security, on time, their problems can become more serious frequently leading to lifelong effects, bigger deprivation plus intense exclusion.

Based on the literature found, studies in this area both nationally and internationally have been scarce to find. For that reason, an international research study by the United Nations International Children's Emergency Fund (UNICEF, 2011) indicated that states should provide help, support, and provide services to assist parents to care for and raise their children. Likewise, counties are obligated to offer suitable support to parents with disabilities so that they can support their children as well. UNICEF (2011) further indicated that children with disabilities hold equivalent rights to family life, and countries should offer early information, provisions, and assistance to children with disabilities and their families to avoid suppression, rejection, mistreatment, and exclusion. UNICEF (2013) also specified that persons with disabilities commonly have additional healthcare needs than others such as immunization, cancer screening, and treatment of infections, as well as needs associated with primary health conditions and impairments. Consequently, (United Nations, 2018) pointed out that individuals living with disabilities endure expenses related to health care, transport, special support or support devices, and adaptations to the homes to support the disability of the child, amongst others. Access to financial services has been documented as important to lifting people out of poverty. The absence of longer-term savings due to poverty or unemployment challenges parents' ability to enhance skills, buy a home, or pay for the education of their children (United Nations, 2018).

South Africa has one of the better policies for children with disabilities, particularly being a co-signer to the United Nations Convention on the Rights of the Child (UNCRC) in 1995 and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 (Tigere & Makhubele, 2019). Nevertheless, a study by Statistics South Africa and Lehohla (2014) revealed

that children with disabilities remain less probable to gain access to suitable homes, water, and cleanliness than their non-disabled equals. It is also revealed that children with disabilities are more probable to reside in outdated houses and unconstitutional communities than their non-disabled equals. Overloaded residing circumstances and outdoor toilets put a huge strain on families and persons living with disabilities (DSD, DWCPD & UNICEF. 2012). It is additionally getting progressively evident that poverty, in connection to disability, must be conceptualized in a multi-dimensional way (Trani & Loeb, 2012). Poverty is defined as a condition characterized by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education, and information. It depends not only on income but also on access to services (United Nations, 1995). Poverty is not entirely related to lack of financial profits but is a much wider comprehensive notion, that includes, for instance, the absence of access to community facilities also the absence of capability to take part in the general public (Comim & Nussbaum, 2014).

As previously mentioned, South Africa maintains a well-built collection of guidelines that speak to the encounters that people with disabilities deal with, all of which nurture into the *Integrated National Disability Strategy White Paper* (Republic of South Africa, 1997). The Integrated National Disability Strategy of South Africa (1997) visions a society for all. In this ideal society, the needs of all citizens including people with disabilities are included in policies, planning, and in the core functions of all institutions in the society ensuring their development potential. This policy is meant to encourage financial addition for persons with disabilities (National Integrated Early Childhood Development Policy, 2015). Nevertheless, in acknowledging that several individuals with disabilities are not able to work, societal safeguard delivery was constructed in the method of a funds-verified disability grant for persons above the age of 18, and the care dependency grant for caregivers of disabled children younger than the age of 18 who require care permanently. These interventions are aimed at offering a salary for persons with disabilities and

caregivers of children who cannot work because of the disability of their child or their disability (Graham et al., 2014).

This current study focused mainly on developmental disabilities which according to (WHO, 2012) are defined as illnesses causing deterioration, activity limitations, and partaking limitations. Developmental disabilities are disabilities that can be intellectual, physical, or both, developmental disability is a larger grouping that begins at an early age and is lifelong (Lindo, Kliemann, Combes, & Frank, 2016). The types of developmental disabilities included in this study are cerebral palsy, autism, Down syndrome, fetal alcohol syndrome, and intellectual disability. Developmental disabilities, like Autism Spectrum Disorders (ASD) and Intellectual Disabilities (ID), are disorders that commence throughout the early years but tend to continue. This suggests that after a child is born with a disability, parents go through greater stressors and difficulties that can affect the whole family's life, shaping the abilities of parents and the parent's ability to meet the child's developmental requirements (McNally & Mannan, 2013; S'lungile et al., 2015). Approximately, 10% of children are affected by developmental disabilities needing to gain access to the health care structure and effective caregiving, frequently during the early years of life and into the adult years (Malhotra et al., 2012).

According to Crawford (2011), parental capacity is the ability to parent in a 'good enough' way that covers all aspects required by a child to develop. Additionally, Ward et al., (2014) refer to parenting capacity as the question of whether parents can meet their children's needs. Consequently, the capacity of the parent is influenced by the conditions of the child's ability and disability (McNally & Mannan, 2013). The study will therefore make use of parental capacity to explore the human capabilities of parents with children with disabilities and to get an insight into the aspects that influence their capability to parent.

The Human Capability by Nussbaum (2003) is a useful framework in understanding the wellbeing and quality of life of parents with children with disabilities. The capability approach is an inclusive framework for the assessment or valuation of a person's well-being, together with the development of the whole countries, socio-economic circumstances, and community arrangements meant for the intention of implementing social and economic policies (Crespo, 2012).

Nussbaum argues in favor of a particular list of capabilities that all individuals ought to have to accomplish the highest level of well-being (Crespo, 2012). From Nussbaum's list, only two capabilities are used for the current study, namely: bodily health and bodily capability. Those two capabilities are selected because they contribute to the capability of parents with children with disabilities to raise their children in a good enough manner meaning that either the presence or absence of these two capabilities have a huge impact on the human capability of parents with children with disabilities. While lack of bodily capability or bodily health on parents can have an impact on parent's ability to care or provide for the child meaning that parents who lack these capabilities might not be able to care for the child in a good enough manner. Therefore, it is the responsibility of the government's its citizens to enable these parents as it is important to support the development of internal capabilities and making environments that enable opportunities for parents with children with disabilities to operate in accordance with these capabilities (Gupta, Featherstone, & White, 2016).

Nussbaum (2011) argued that combined capabilities are highly relevant to internal capabilities, internal capabilities are also identified as the individuals' characteristics and are developed conditions such as bodily development, religious choice, character qualities, academic and emotional capacities, conditions of bodily health, and well-being, self-knowledge, skills of insight and movement required functions to perform necessary things. These capabilities are chosen for the study because the individual characteristics mentioned above (which include the pre-existing basic capabilities by activities such as training, education, and exercise) play a critical role in

shaping the human capability of parents with children with disabilities. Nussbaum (2011) further indicated that combined capabilities are being greatly related to the features of an individual or internal capability. The two are linked because, combined capabilities are freedoms or opportunities created by a mixture of a person's capabilities and social, political, and economic settings that sustain these capabilities. Nevertheless, internal capabilities are established in relations with the community, family, economic and political surroundings (Gupta et al., 2016). This means that combined capabilities and internal capabilities are closely linked to each other and that one cannot operate in isolation to another. Also, internal capabilities are established in collaboration with the community, political, financial, and family environments. Combined capabilities are defined as freedoms or opportunities formed by a blend of individual capabilities and political, community, and financial situations that are backing these capabilities. The study only focused on combined capabilities because combined capabilities consider a person's surroundings and their internal capabilities, which play an important part in parents' ability to parent in a good enough manner.

Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) acknowledges the right of every person to the fulfillment of the maximum achievable degree of bodily and psychological health (Grover, 2011). The responsibility of the governments and the public is to make surroundings that enable prospects for individuals to operate under these capabilities and encourage the expansion of internal capabilities (Coomans, 2011). Although research has been previously done regarding parents taking care of a child with a disability, the emphasis has not been upon the human capabilities of parents or caregivers, nor the freedoms and opportunities. This study therefore, explored if parent's bodily health, bodily integrity, and combined capabilities allow the parents to attain their child's developmental desires, to understand their child's disability and developmental milestones of their developmentally disabled children (0-8 years), and to understand the effect poverty and inequality has on caregivers.

1.2. Problem Statement

The policies to assist children with disabilities so that the responsibilities of parents can be reduced are there, but the problem is that the parents of children with disabilities are also exposed to poverty along with the lack of needed economic support; do not have reasonable contact to information necessary to provide appropriate care for their children; and, have insufficient community support (DSD, DWCPD & United Nations International Children's Emergency Fund (UNICEF), 2012). Assistance for children with disabilities such as home and community-based basic education opportunities have been identified as not easily available (National Integrated Early Childhood Development Policy, 2015). This, in turn, has been a great challenge for the primary caregivers of these children. Most research done previously focuses on the wellbeing of caregivers of children who have disabilities. Outcomes from the research were done by Murphy et al., (2007) point out that caregivers of children with disabilities express undesirable bodily, behavioral, and psychological health consequences of long-term, informal caregiving. Another study by McNally and Mannan, (2013) also indicated that when comparing primary caregivers with children with no disability and primary caregivers of children with disability, it has been found that in most cases those with disabled children are affected mostly by negative bodily health signs and undesirable stigmatization from their surroundings that leads to reduced inner (psychological) comfort. This indicates that there are limited or no studies focusing on the human capabilities of parents with children with disabilities hence this current study , therefore, aimed at exploring the human capabilities of parents with children with disabilities.

1.3. Research question

- What is the human capability of parents/caregivers with children with a developmental disability?

The following are the sub-questions of the study:

1. What are the bodily health and bodily integrity capabilities of parents and/ caregivers with children with developmental disabilities?
2. How is the government assisting parents and or caregivers of children with disabilities in enhancing their capabilities?
3. Which programmes are available to promote the freedoms or opportunities for parents and/ caregivers of children with developmental disabilities?

1.4. Aim and objectives of the study.

The research question has then led to the establishment of the aim and objectives of the study.

1.4.1 Aim

The study aimed to explore the human capabilities of parents with children with disabilities.

1.4.2. Objectives of the study

The objectives of the study were to:

1. Explore the bodily health and bodily integrity capabilities of parents and/ caregivers with children with developmental disabilities;
2. Explore how the government assists parents and/ caregivers of children with developmental disabilities in enhancing the human capabilities of parents;

Explore the programs available to promote the freedoms and/or opportunities for parents of children with developmental disabilities.

1.5. Research methodology

To explore the human capabilities of parents or caregivers with children with developmental disabilities a qualitative research approach was used. A qualitative approach has allowed for an

expansion of understanding the experiences of the participating parents both in Kraaifontein and Fisantekraal, and as a result, a picture from their founded reality about the human capabilities, freedoms of parents or caregivers with children with developmental disabilities is illustrated (Safe, Joosten & Molineux, 2012). Qualitative research was suitable for the study since it embodies the present reality by capturing the paradox, confusion, and involvedness that allowed the researcher to sort out examples of importance during the interview sessions (Braun & Clarke, 2013). The qualitative research method was selected because it was more flexible, meaning that there was a better understanding between the researcher and the study participants which resulted in greater freedom in between (Denscombe, 2014). For instance, qualitative research asked open-ended questions that allowed the participant to respond freely in their own words in detailed responses from parents of children with disabilities rather than getting yes or no answers.

1.6. Ethical considerations

Permission from the Humanities and Social Science Research Ethics Committee (HSSREC) was requested before the study was done. With regards to professional practice, an assessment of ethical standards that gives rules to professionals against professional's wrongdoing was also considered (Sarantakos, 2012). As stated by Bryman (2015), research ethics have three objectives namely, to keep participants protected, to guarantee that people taking part in the research area in a way benefiting from the study whether independently, as a collective, and or the whole community and to look into ethical consistency of other research interests taking place and developments, taking into consideration matters like the risk management, discretion, and the informed consent practice.

Upon the approval of the study, the research has promoted respect for all human beings who took part in the study and protected their health and rights. The researcher also briefly explained the study by reading the informed consent (Appendix 2) and the information sheet (Appendix 1) to

participants in both Xhosa and English based on their preference (World Medical Association, 2001). Moreover, the researcher further informed the participants of their right to voluntarily participate in the study and withdraw from participating at any given time. Furthermore, counseling and assistance were recommended to participants who need it by giving out the necessary information on where to go for assistance. During this study, things such as anonymity and confidentiality were given particular consideration and made especially understandable to participants. Ritchie et al., (2013) put forward that anonymity represents the identity of those taking part not being recognized outside the research group. Sarantakos (2012) states that confidentiality means the contribution of the participants should not be made available to other people. Therefore, in the current study participant confidentiality was sustained at all times.

1.6.1. Informed consent

Informed consent allows the participants the privilege to understand what it means to take part in a specific research study so they can choose in a whether they want to take part in a study or not. Informed consent is one of the most significant tools for safeguarding respect for participants when conducting research (Clark, 2012). Ritchie et al., (2013) adds that informed consent (see Appendix 2) is an important in ethical considerations. Equally significant, informed consent is one of the most central tools for guaranteeing respect for participants throughout research (Van den Berg & Struwig, 2017). The researcher must present the participant with information about the intention of the study, who the research group is, how the data will be utilized, and what involvement he or she will need them. For that reason, informed consent for the current study was done via written consent. That means information about the study was given to the participants, the aim and objectives of the study were also clearly explained so that they would understand the research before agreeing to take part.

1.7. Significance of the study

The study contains useful information for relatives of children with disabilities as data that was collected contained different experiences of parents or caregivers with children with developmental disabilities. The data might also be of importance to policymakers who are responsible for creating and implementing policies that are aimed at helping parents or caregivers of children with disabilities. The study might furthermore have an impact on the government so that the issue of parenting or caring for children with developmental disabilities can be further looked into in terms of creating more opportunities and assist parents or caregivers caring for disabled children. Moreover, the study will also be some form of awareness to the community at large and help reduce stigmatization against families and people caring for people with disabilities and who are living with disabilities particularly children, and help them assist people with disabilities where they can. Ultimately, the study has equally benefited parents and guardians raising children with developmental disabilities to assist them to manage their situation better by building awareness and insight on parents and those caring for the disabled children and to equip them about the importance of their wellbeing when taking care of a child with a disability.

1.8. Definition of terms

Capabilities: are important things that people can be or do, and which they have reason to treasure, they are freedoms to take part in valued community tasks and actions, what people can be given and can do both their capacities, and environmental limitation and opportunities (Shinn, 2015). Stewart (2013) further added that, the capabilities approach has always well-defined capabilities as being relevant to people, and that the intention of development is to develop individual capabilities and freedoms. To provide the conditions for individuals to flourish is the main value of societal capabilities. Good societal conditions have an impact on both the outcomes

(functionings) of individuals in a certain community and the upcoming generations (as well as children already born).

Human capabilities: Dawes (2021), defines human capabilities as human beings' ability to lead lives they can afford and to develop the substantial options they have. It is an economic theory formulated in the 1980s as a different approach to welfare economics. The capability approach highlights the importance of what people can do (West, 2002).

Freedoms: It is a condition in which people can select their objectives for their lives and obtain ways or opportunities for accomplishing those objectives, meaning what an individual is free to do and accomplish in the pursuit of whatever intentions or qualities the person sees as meaningful (Nussbaum & Sen, 1993).

Opportunities: are defined as individuals' capabilities to flourish or achieve well-being too and be what they desire to be as an individual and the freedom to choose between different ways of engaging academically (Nussbaum, 2003).

Children with a disability: children who have an impairment, such as physical (loss of the legs); sensory (loss of sight); intellectual (challenges with learning) (World Health Organization (2018).

Parents: the study made use of the word "parents" to refer to the fathers, mothers, grandparents, legal caretakers, or any caregivers of children given that they are the primary caregivers and accountable for the maintenance of the child. According to Hiebert-Murphy, Trute, and Wright (2011), a parent is also known as a guardian or someone who ensures that their child is well taken care of at all times.

Parenting: the method of empowering and supporting a child from early stages to maturity, this takes into consideration the social, physical, emotional, and intellectual development of children (Hartas, 2014).

Developmental disability: disability means impairments in the bodily (such as loss of sight), mental (that might interfere with an intellectual ability such as learning). This means that they are lifelong, critical impairments. Or the impairments can be equally psychological also bodily, like Down syndrome as an example. The impairments frequently last for a lifetime and can influence daily living (Lindo et al., 2016).

Family: A group of individuals combined by the joints of marriage, blood, adoption, or cohabitation, distinguished by a shared house or home, relating, and communicating with one another in their family function or responsibility, upholding a shared culture and administered by family guidelines and procedures (National Early Childhood Development Policy of the Republic of South Africa, 2015).

Capabilities Approach an interdisciplinary tool that is can be applied in several situations and surroundings such as an evaluation of the quality-of-life issues (Jirgensons, 2015).

1.10 Thesis chapter outline

Chapter one consists of the background and rationale of the study. The chapter is an introductory chapter of the study and describes the research problem or research question and puts down on paper the reasoning behind it. For the case of this study, the reasoning is called a theoretical argument. To justify the study, Martha Nussbaum's human capability approach was used as a theoretical framework, to understand, explain, or further describe the phenomenon of the study. It further consists of an understanding of the extent to which the human capability of parents or caregivers of children with developmental disabilities can be affected by their child's disability. This chapter also entails the problem statement, which clearly states the intention of the research. The chapter includes the necessity for research that enables a better insight into the human capabilities of parents/caregivers with children with developmental disabilities is highlighted. The chapter also contains the, aim, and objectives plus definitions of the study.

Chapter two comprises the theoretical framework of the study. In this chapter, the study discussed Martha Nussbaum's human capability theory which is used as the underlying framework for the study to evaluate the quality of life of parents or caregivers with children with developmental disabilities. The theory is mainly used to guide the study. In a nutshell, the chapter looks at scholarly works allied to the human capability of parents or caregivers with children with developmental disabilities as well as the influence of raising a child with a developmental disability on parents or caregivers.

Chapter three reviews literature, this chapter evaluates what has already been written in the human capability of parents with children with disabilities, and child disability research. The literature mentioned in this chapter supports the theoretical (human capabilities) argument being made and demonstrates that the author understands the main concepts and results that connect to the human capabilities of parents with children with disabilities. For that reason, headings and sub-headings are used in this chapter to discuss major issues related to parenting a child with a developmental disability from a human capability perspective are thoroughly discussed in this chapter.

Chapter four outlines the research methods applied to the study. The methodology chapter gives necessary information about the methodology employed in the study. This chapter includes the following: research methodology, research design, data collection procedure, and data analysis. The section contains an explanation of the research procedure, which involves the selection of participants, research setting, data collection tools, data collection procedure, and approaches used to analyse data. The chapter also discusses ethics that were considered in carrying out this study.

Chapter five focuses on presenting and discussing the study findings. In addition to this chapter, themes for the study are identified, the identified themes are presented and discussed in detail in this chapter. Therefore, this chapter demonstrates the results of the analysis, in order by the

research question, and any other results of further analyses. The chapter looks further into the results and explains them considering the research questions and discuss them in combination with the available literature on the human capability of parents with children with disability. Results are demonstrated without interpretation; interpretation is kept for the discussion in this chapter.

Chapter six presents the summary, conclusion, and recommendations of the study based on the main findings of this study.

CHAPTER TWO

THEORETICAL FRAMEWORK

2.1. Introduction

This chapter presents the theoretical framework of the study by using Martha Nussbaum's approach to human capability. Firstly, the chapter will be the discussion on the capability approach and then a brief discussion on human capability including the ten basic capabilities that includes an in-depth discussion of two components from the ten central human capabilities proposed by Nussbaum's theory, which are the focus of this study. After this, bodily integrity and bodily health as a human capability are further explored. Then finally, the researcher discusses combined capabilities as a human capability.

2.2. Capability Approach – Amartya Sen

Amartya Sen is the founder of the Capabilities Approach, in 1998 he won a Nobel Prize in the field of economics (Gupta et.al, 2016). The approach originated from his work in addressing the quality-of-life problems in India (Jirgensons, 2015). The capability approach is a human development indicator that measures human capacity and its potential to change individuals' lives and present new prospects (Jirgensons, 2015). Sen's prime use of the capability approach is presented and made in a space within which evaluations of the quality of life are most successfully made (Williams, 2020). The interest of the capabilities approach is that it provides a quality-of-life measure and is focused on what people can be or can do, also offers a basic interpretation of what is needed to live a good life (Nussbaum, 2001). The most important concepts that are the focus of the approach are the means obtainable to an individual; what that person is and what he/she is doing. Also, the influences that affect a person's capacity to convert means into functioning's and the mixture of being and doing that a person has the actual freedom to achieve

(capabilities) on an individual, biological, community influences. A person's capabilities represent the actual freedom of an individual to select between various types of life that they may value and has reason to value and amongst various functioning blends (Gupta et al., 2016).

To fully distinguish the capabilities framework, the two main concepts (functioning and capabilities) need to be understood clearly. Functioning's are estimated states of being such as prosperity and well-being of individuals, for example, they are also identified as things or activities in which individuals take an interest. Capabilities are opportunities to accomplish such functioning's (Mitra, 2006). The capabilities depend on characteristics accessible to the person such as the person's bodily features, monetary status, and academic level as well as the socio-political background that acts to improve or limit capabilities. For instance, taking social-political feature as an example, this suggests that social-political senses allow individuals to measure how fulfilled they are around what they can accomplish and develop meaningful decisions as regards to what they desire to be and do (Deneulin & McGregor, 2010). Sen (1999) and Nussbaum (2001) refer to things that hold back or limit a person's capabilities as 'unfreedoms. Growth consists of intensifying or increasing the "freedoms and absence of the causes of un-freedoms, such as poverty and poor economic opportunities" (Sen, 1999, p.3) to facilitate people to attain functioning's. Individuals living in poverty on a capabilities viewpoint are repeatedly deprived of the means for basic capabilities, such as suitable nourishment, warmth, and adequate housing, as well as social and environmental (conversion) factors that would strengthen their capabilities and functionings (Gupta et al., 2016).

Nussbaum (2011) claims that an individual's capability allows them to accomplish human functions. For that reason, capabilities must therefore be understood as what people are essentially capable to do and being. According to Nussbaum, it is an individual's freedom to choose when or where to apply these capabilities and how they want to make use of them (Peleg, 2013).

Peleg, (2013)'s study has put an emphasis only on Martha Nussbaum's version of the capabilities approach and is applying to her theory every time it refers to "the capabilities approach" since only two capabilities have been selected from his ten-capability list. The key idea of the capability approach is that social activities should purpose to expand people's capabilities which is theirs. The capability approach viewpoint is based on people's freedom to promote or achieve what they value to do and be, which in turn should be maintained by the social activities which are aiming at increasing people's capabilities (Nussbaum, 2000).

Nussbaum (2000, 2001, and 2003) pointed out that the fact that you are being a human being means that you have the same dignity and worth, the emphasis must be put on what people are essentially able to do and to be and this means that equal social responsibility of people with bodily and psychological disabilities should be recognized. Structures of essential rights to the people that are there to simplify the structure of human capabilities must be provided by the government as its obligation (Nussbaum 1987; 2003). Correspondingly this is clearly stated in the South African Constitution in the Bill of Rights Chapter 9. Additionally, the notion of the person as a social being an impartial claim from the capability approach upholds that the dignity of all individuals should be always maintained despite a person's capability to do a lot of work (Nussbaum, 2000).

The capability approach agrees with the fact that individuals' structural differences like gender, ethnic group, disabilities, and class are of vital importance to the Capability Approach's theory of societal justice (Carpenter, 2009). Individuals affected by poverty are considered as 'capability deprived' because due to poverty, their capability to make valued choices and contribute completely to the community is affected (Sen, 1999). Therefore, as Sen has stated, poverty results in the lack of numerous different basic capabilities not only about physical possessions but other capabilities as well such as having food, having appropriate housing and having sufficient clothing and avoiding unnecessary illness or injury, and being involved in community activities such as

participating in the community, to have the ability or courage to be seen in public without the worrying about what people are going to say (Sen, 1995, p. 15).

A person's surroundings factors such as the ecological and community conditions, both current and historical are influenced by their capabilities. To examine an individual, it is of vital importance to take into consideration both the individual and the place they reside in (Smith & Seward, 2009). When one lacks a particular capability, it is important to determine the reasons behind the lack of capability. When considering the absence of a capability, attention is directed to the appropriate causal pathways responsible. For instance, the capability to look after a child is subjected to having suitable resources such as suitable baby care products and baby food, knowledge, and skills of caring for babies, baby medication, and a child-friendly environment from the family from which socio-cultural norms allow one to take on childminder tasks (Entwhistle & Watt, 2013). Aslam, (2013) confirms that houses with members with disabilities are at a greater risk of living under poverty and have smaller incomes than other houses.

Studies by Nussbaum (2005); Sen, (1999) affirms that there are so many ways that can limit a person's capabilities, a practical example is people living in poverty, a society that is male-dominated where women are denied leadership roles, having a disability in a community that criticizes or not taking into consideration people living with disabilities, and/or by living in a society where to a marginal cultural group that is undermined by the dominant group. On that note, for this current study, the researcher viewed child-rearing a child living with a disability as a multidimensional matter; these parents experience un-freedoms because of so many challenges or lacks faced (from a capabilities viewpoint) and limit the chances of enhancing or making their lives better. The researcher, as a result, has considered the parental capacity to consist of issues of income and material assets, education, health, occupation, and social capital and measured these in various ways throughout the study.

2.2.1 Parenting children with a disability within Capability's Approach (CA)

The capability approach acknowledges that functioning's, or what parents achieve during their interactions with children, are bounded by their living conditions and parents' ability to convert opportunities into functioning's (access to real opportunities and their capacity to make use of them) (Hartas, 2014). Parents' ability to care for their children adequately is also affected by the presence of wider deprivation including poverty, poor or overcrowded housing, and unemployment (Ward et al., 2014). Moreover, Gupta, Featherstone, and White (2016) added that the key to promoting children's well-being is to help their parents, and by increasing the living standards of poor families, including the improvement of social housing, schools, and other public services. Similarly, Nussbaum (2011) uses the idea of capabilities to develop thinking about social justice, and a state's basic responsibilities towards its citizens. Her central capabilities are closely related to rights; like rights, they include the idea of entitlement. Therefore, functioning is related to the different conditions that surround people's lives. For example, educated parents may be in a better position to offer learning support at home and create learning conditions that are conducive to child academic achievement (Hartas, 2014).

Caring for a child with additional needs can increase parents' stress levels and escalate other problems such as mental health problems. Some mental health problems may also reduce parents' awareness of their children's basic needs or their ability to meet them. Impaired personality functioning and mental health problems such as anxiety disorders, depression, and some psychotic illnesses may reduce parents' ability to be reciprocal, involved, and encouraging with their children (Ward et al, 2014)

To understand the human capability of parents with children with disabilities, it is, therefore, essential to recognize the bodily health as well as bodily integrity of parents given their environmental factors in meeting the child's developmental needs.

2.3. Human Capabilities – Martha Nussbaum

The capability approach was used by Martha Nussbaum as the starting point for a shortened theory of justice (Nussbaum, 2001). It was further argued by Nussbaum (2003) that the capability approach from a viewpoint of moral-legal-political philosophy with the recognized aim to explore political values that a government must guarantee all its citizens through its constitution.

Central to Nussbaum's capabilities approach is the idea that justice should be defined in terms of people's capabilities to do and be different things (Holland, 2008). For instance, on Nussbaum's (2000, p. 78-80) account, part of what justice requires is that people can "hold property" and the capability to "move freely from place to place." Nussbaum (2000), argues that without these capabilities, women are especially subject to common forms of oppression and deprivation, and they will consequently remain unable to live a life that is "worthy of the dignity of a human being." Therefore, from the viewpoint of the capabilities approach the evaluation of social policy and social arrangements starts by looking at how internal and external circumstances shape the capabilities of people in life. Then it is a good position to start evaluating and reasoning on what justice is perceived as and what it requires or constitutes (Holland, 2008).

That is to say that the appeal of the capabilities approach is that it provides a pluralistic account of what we need to live well (Nussbaum, 2011). It is important to keep in mind that Nussbaum's capabilities approach is a partial and not a complete theory of justice. The 10 capabilities on Nussbaum's list represent a minimum standard of justice. This means that these are basic entitlements such that, without providing each and all of them, a society cannot lay claim to justice (Nussbaum, 2001). Hence, if a society neglects only one of those capabilities, for instance, the

capability of bodily health, this society is not a just one (Nussbaum, 2000). This means that every person needs to have a whole set of capabilities. The idea behind this is that you should not be forced to choose between two valuable opportunities such as holding a job that provides some financial freedom and caring for your children. Rather, both capabilities should be open at the same time. For that reason, the role of governments should be to provide a framework of core entitlements that facilitates the building of human capabilities (Nussbaum & Sen 1993; Nussbaum, 2002).

Nussbaum (1987) further reveals that all capabilities are of equal standing, and there is no lexical or another commanding among them. All of them need to be provided at or above the threshold level where a flourishing human life becomes possible. In the same way, people should not be homogenous or as having equal opportunities. Gender, disability, age, ethnicity, or illness have an excessive influence on levels of income and accessibility to social services, which are essential to sustain comparable standards of living. For example, a parent of a child with a disability needs to spend a larger percentage of her income on buying medications and treatments (and needs more access to health care services) than a parent with a child without a disability and the same level of income spends on her child's health. Therefore, to maintain a similar standard of living, these two peoples need dissimilar resources (Peleg, 2013).

Nussbaum's capabilities approach views the government as having the duty to provide the social basis of the ten capabilities at a suitable point at which they start to experience the capability level for each (Nussbaum, 2000, p. 75). Taking into consideration, how much an individual needs to reach the point at which they start to experience the capability may vary from one to another. Therefore, parents of a child who needs more resources to attain a certain capability also have a reasonable claim to the development of that capability. What is important for justice is the result of reaching the point at which they start to experience the capability level, rather than the resources needed to do so (Jirgensons, 2015).

A study by Alias and Dahlan (2015) made efforts to provide an exploration of one's life experiences in raising children with dyslexia. The study employed a qualitative research methodology. Also, convenience sampling was employed to recruited ten mothers who have a child diagnosed with dyslexia as participants of the study. The responsibility of these mothers was to care for children aged 7 to 12 years old. Outcomes from the study discovered that the majority of the mothers expressed that they had insufficient knowledge, time constraints in managing their dyslexic children, multiplying monetary challenges, school challenges, and discouraging feelings regarding the child's state of health.

Because a parent with a disabled child might not be capable of doing many things that a parent of a child without disabilities can do, the capabilities approach recognizes varying needs of resources, with the same resources. As a result, parents with a disabled child should purely obtain additional resources (Resch et al., 2010).

As mentioned by Gupta et al., (2016) that to function can occur even with the same set of personal means for different reasons, such as:

(1) Individual differences in physical and psychological characteristics such as, for instance, disability or illness; (2) Differences in non-personal resources such as health care or community resources; (3) Environmental varieties such as physical or built environment or threats from community crime; (4) Differences in qualified position as against others, for instance, relation income poverty in a rich community may translate into total poverty in the space of capability; (5) Distribution within the family - distributional rules within a family determining, for instance, the sharing of food and health care amongst children and adults, males and females.

Therefore, environmental, and social surroundings both past and present drastically influence a person's capabilities (Graham et al., 2014). As a parent of a child with a disability, you bring historic, medical, educational, and personal understanding of your child, unique, and important

human being. Individuals working with your child for a few hours a day or even for a few years cannot know the child as you and the family do (Cleaver & Unell, 2011). That is why the Individuals with Disabilities Education Act (IDEA) 2004 puts emphasis on the role of parents in planning and monitoring their child's educational journey.

2.3.1 Ten basic human capabilities

Nussbaum (1987, 2000, 2001, 2003, and 2011) developed and argued for a distinct but universal list of central human capabilities that she proposed must be included in all structures. This means that none of the capabilities from her list is better than the other, meaning that all the capabilities in her list should be equally respected and be treated with the same value as the other, if not then it means justice is not served. With the focus of the design of a just constitution, Nussbaum proposed a list of ten fundamental human capabilities. In quite a few of her publications Nussbaum has specified the list in more detail (Nussbaum 2001; 2002; 2003; 2011). The list is as follows:

- (1.) **Life** - Being able to live a desired life, a life that is whole and without regret. This means a life that is completely lived. Unfortunately, because of different situations encountered such as illnesses or injuries that might threaten an individual's life. This involves avoiding escapable illnesses and impulsive death and having a longer life. In the case of this study, an example of this capability would be for parents to not live a life that is not completely lived because of the care burden caused by little or lack of sleep and dealing with the strain to cope with the child's medical needs.
- (2.) **Bodily health** means being able to live a healthy life; a life that is free from sicknesses or away from anything that threatens one's quality of life. This capability takes into consideration having access to any medical support as required. Access to food and the ability to do things that complements one's health. This capability involves having enough food to eat, nourishment, being in good health, being free from diseases and having a

properly placed to stay (adequate housing). For the case of parents with children with disabilities for instance, it is important to be healthy, have proper housing and nourishment so that they can take care of their child, and ensure that the needs of the child are taken care of.

(3.) **Bodily integrity** – the capability to travel where you want to travel. This capability is also referred to as the bodily needs of an individual, this means the ability to satisfy healthy body needs and it considers being free from any kind of bodily injury caused by attack and abuse of any kind. This capability is involved travelling or moving around. For instance, traveling can be for various reasons including, going shopping, going to the clinic, or just travelling for any kind or reason that requires to move from one place to another. Patosalmi (2009) further indicated that the basis of Nussbaum's concept of bodily integrity is the conception of the autonomous subject. Nussbaum's theorizing is based on the clear-cut idea that an individual is in control of her or his own body and should be the only expert in decision-making about the body. The body is understood to be a physical object that has fixed boundaries, which are supposed to be respected. This subject has a mind, which is protected, for instance, by securing freedom of speech and religion, and a body, which is protected by securing the right to bodily integrity. The individual is understood to make realistic choices, therefore protecting the ability to make a choice is also a significant feature for the human being.

(4.) **Senses, imagination, and thought** – This capability refers to the ability to see, smell touch, taste, and hear. The freedom to think logically, imagine, and think independently. Being educated or academically qualified allows this capability to take place on a high level. This capability also includes an individual's ability to express themselves whether in a political and or religious way. This capability entails of being well-educated or knowledgeable and that includes cultural and intellectual pursuits. An example of this capability involves

parents of children with disabilities ensuring that they are well educated and informed about their child's disability, getting all the knowledge and information they can, so that they can find ways to better cope with their situations.

- (5.) **Emotions** – The ability to be emotionally connected or to love other things or people besides ourselves. This capability involves all the emotions that people go through such as fear, excitement, anger, and joy. This capability includes being happy and being close to people that make one happy. An example of this capability would be for parents with children with disabilities to have people around that they love besides themselves, people that makes them happy as happiness is an important factor for every individual.
- (6.) **Practical reason** - The ability to determine between the good and the bad, to think reasonably about life and the reason for their existence. An individual's sense of right and wrong is at the core of this capability. This capability includes taking part in the life of the community. For example, parents of children with being involved in projects that are happening in the community such as feeding programmes or disability support groups happening in one's community.
- (7.) **Affiliation** - The ability to be able to live with other people, share things with them and not live or do things in isolation. Being able to assist each other where possible, an act of Ubuntu towards others, being the helping hand and ensuring that justice is served, and the rights of others are not violated. For an instance, for parents of children with disabilities to share things for those in need or assisting where possible in the community and getting assistance and support when required. Meaning being in a community that helps when one is in need.
- (8.) **Other species** - The ability to live with different types of animals that exist on earth. Being able to enjoy wildlife and appreciate its beauty. For instance, the ability to embrace and

live in harmony with different animals such as dogs, birds, cats, etc., a community that is surrounded by different plants and takes care of them.

(9.) **Play** - Being able to laugh, play games, and mostly be entertained. This means having fun and leisure without being stopped or judged.

(10.) **Control over one's environment** -Having the ability to take part in any political party of their choice and to engage in activities of their choice. The ability to own a house, to look for a job and work, be treated fairly at work. Being free from unjustified search and confiscation. For instance, the ability to have employment, and to be engaged in leisure pursuits of choice such as the gym.

As stated by Nussbaum (2011), given the capabilities approach an individual cannot be said to flourish, if the person is not able to perform roles that take part in the capabilities. This brings up interesting questions with parents or caregivers of people with disabilities as they have the responsibility to care for and ensure that all the developmental needs of the children are attained. The study addresses the question of the human capabilities approach through Nussbaum's capabilities (with only two selected capabilities), bodily health, and bodily integrity. The two selected capabilities are selected because they are vital parts of well-being for parents of children with disabilities and as mentioned previously that the two allow parents to attain their child's developmental desires, to understand their child's disability and developmental milestones of their developmentally disabled children (0-8 years) and enable the researcher to explore and understand the effect poverty and inequality on caregivers as well as exploring their general wellbeing given their circumstances. The two selected capabilities will be further discussed:

2.3.2 Bodily Integrity as a Human Capability

Holland (2008, p. 322) describes bodily integrity as "being able to move freely from place to place; having one's bodily boundaries treated as sovereign, that is, being able to be secure against assault,

including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and choice in matters of reproduction”, and to be free from attack, stigma, and any violent behavior associated with their children’s disability (Nussbaum, 2011). On the other hand, bodily integrity is understood by Nussbaum (2003) as the freedom to travel to wherever you feel like traveling. The ability to be in good physical shape and to be safe from any kind of harmful behaviors. According to Nussbaum’s “bodily integrity is a feature of basic human capabilities. The basic human capabilities are meant to define characteristics of the human being, and bodily integrity is understood to include, among others, freedom of movement, respect for bodily boundaries, and opportunities for sexual satisfaction and reproductive choice” (Nussbaum, 2000, p.78). Nussbaum’s notion of bodily integrity as the foundation is the beginning of the self-governing matter. Nussbaum’s notion is grounded on the absolute idea that an individual should be the only expert in making judgments about the body and is in charge or has power over his or her own body. The body according to Nussbaum’s capability view, is understood to be a bodily being that comprises a range of unchanging restrictions, which must be valued. This viewpoint also acknowledges the total difference between the mind and the body (Nussbaum, 2006).

Therefore, to support this capability in the instance of parents of children with disabilities who undergo an absence of bodily integrity as capability deprivation the intention for putting to view this capability is to acknowledge the society’s obligation to offer the social conditions (such as basic needs for people, proper health care, employment, etc.). To increase the freedoms, financial and commercial opportunities of people, it is of vital importance to take bodily integrity as crucial freedom. Following the capabilities approach, the government is initially accountable for providing the social foundations of the ten central capabilities, through its public policies (Nussbaum, 2000). This approach is of benefit to the parents with disabled children mainly because they need support and financial aid if they are to provide those children with a dignified life commonly experience different and more challenges than other parents (Gundersen, 2012).

Moreover, African Child Policy Forum (ACPF) (2011) also added that when parents have a physically disabled child, traveling with them can be a bit complicated and challenging because of the use of wheelchairs and lack of transportation problems, this, in turn, is affecting the parent's bodily integrity. Without physical assistance from their parents, some of the children with physical disabilities find it hard to go to places such as parks to play without the help of the parents. However, using assistive machines or gadgets such as mobility or electric wheelchairs, movement, daily living, and personal freedom of these children can be enhanced.

The two selected capabilities from the list can be applicable for parents or caregivers of children with disabilities for two reasons. Firstly, it meets the parent's or caregivers' needs through the support for the capabilities of bodily well-being. As discussed by Crawford (2011), the bodily well-being of parents or caregivers will be met by providing stimulation for positive parenting, enhance parental capacity, and support parents, this shows a clear obligation on the government to not merely allow for such positive parenting but to in point of fact offer resources for such parenting. Secondly, a few of Nussbaum's ten capabilities are classified as basic human rights in South Africa (that defends an individual's right to health, bodily integrity, life, affiliations) that are essential for each human being, these rights have universal acknowledgment (Dixon & Nussbaum, 2011).

A suitable community according to capability context, ought to establish the societal conditions that look into backing bodily and psychologically disabled children's and adults' needs for care, education, self-respect, movement, and relationship (Gundersen, 2012). Children with special challenges due to their bodily and or intellectual disabilities depend on their parents or guardians because not all beings can obtain their capabilities without assistance, therefore, parents or guardians play an important part in recognizing that the needs of children are met and their capabilities accomplished to the uppermost imaginable point, (Nussbaum, 2006). That kind of caregiving does not only require a just society, but the support is given to the caregivers by the

people in the society to ease the caretaking burden. Additionally, a fair community must give recognition and reward for the huge amount of care work done and not take advantage, meaning that it must make arrangements for care in a way that does not take advantage of the caregiver (Nussbaum, 2006).

Relating to capability, a disability is a deprivation, that is, a lack of opportunity to be or to do, that results from a person's characteristics, resources, and the environment (Stein, 2017). This, therefore, results in a great challenge for parents with children with disabilities since they must care for their disabled children. For that reason, taking care of a child with impairments might increase stress, might also impact the psychological and bodily health, it might be challenging to find appropriate and inexpensive childcare for those that are working, and has an impact on employment decisions, education, or any form of training taken, giving birth to other children, and depending on community assistance (Ha et al., 2011). Thus, the focus is on two capabilities, as discussed above out of the ten central capabilities by Nussbaum.

2.3.3. Bodily Health as Human Capability

Health is the second element called bodily health on Nussbaum's capability list. Nussbaum (2000) appears to have adopted the WHO's (2012) idea that health is overall bodily, mental, and community well-being. The accomplishment of other capabilities is related to health; therefore, health has been declared crucial when discussing reproductive health. According to Holland (2008, p.322), bodily health entails "being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter". Health according to Nussbaum (1987), is more than just an absence of disease but merely the ability to avoid being sick or illness and injuries for that reason, being affected by any form of illness means the absence of this capability (Venkatapuram, 2013). For instance, either not being adequately nourished or not having the ability to be nourished (e.g., provide food oneself) is not enough to be labeled as being unhealthy.

Nussbaum (1987) maintains that bodily health capability includes living a healthy lifestyle and not in a state where a person's quality of life is affected by illnesses. Bodily capability also means having access to healthy food, required medical assistance, and maintain health by doing any form of workout. In the case of this study, parents of children with disabilities should not be deprived of this capability as they must have good health, suitable housing, and food (Nussbaum, 2011). Therefore, Nussbaum (2011) points out that the human capabilities perspective treats physical belongings such as shelter, assets, and food as valuable to every individual (Holland, 2008).

An international study that was done by Ahmadizadeh et al., (2015) investigated the factors associated with quality of life in mothers of children with Cerebral Palsy (CP) in Iran, Hong Kong. The investigation was made through the made cross-sectional method. It was, therefore, revealed that bodily and psychological stress for parents taking care of children with CP was one of the consequences they experience, particularly those who are caring for children who need special and lifelong care or assistance. This brings to light that taking care of a child with a disability has an enormous impact on the quality of life of parents or carers. The study further revealed that mothers who have a child with CP and intellectual disability are greatly associated with an unhealthier level of quality of life while being employed full-time is linked with a healthier level of quality of life. Inadequate or scarcity of health significantly reduces all parts of bodily health capability. The unequal distribution of health capabilities may, therefore, affect social justice in several ways (Sen, 2002).

As indicated by the WHO (2011), social influences, such as nourishment, poverty, climate, clean water, and hygiene, the circumstances a person is working under or gaining entry into the health care system have an impact on an individual's health. The Department of Social Development/Department of Women, Children, and People with Disabilities/UNICEF (2012) revealed that the impact of inadequate living settings is particularly unfavorable for children with disabilities. This is illustrated by Statistics SA's Community Survey 2007, that when comparing

children with disabilities and those without disability it has been found out that, disabled children are more likely to lack access to adequate shelter, water, and hygiene as compared to their non-disabled equals. It is further highlighted that in most cases children with disabilities tend to live in informal settlements or houses that do not accommodate their conditions. The places that they live in are overloaded residing environments with outdoor restrooms place huge stress and burden on children with disabilities and their families who must assist them.

A study by Hung et al., (2010) also highlighted that a child's negative rehabilitation result is a consequence of the psychological health of parents since they may be poorly affected because of the high level of care needed by their children. A different study by Ha et al., (2011) further documented that, when comparing parents with children with disability and those with children without disability, in most cases having a child with a disability can have bad influences on parents such as poor mental well-being, additional bodily health signs, and unhealthy outcomes. Some of the stress and depressive symptoms had physical health elements, and the overall health and exhaustion consequences conveyed a larger bodily than mental symptom weighting (Masfield et al., 2020).

A study by Ruger (2006) indicates that health care has been associated as a special public right by the current frameworks in medical ethics, as well as those that are made up of health evaluation. The study additionally specified that less attention has been paid to worldwide fears of justice concerning health by most academic fields. This favoritism seems to stem from at least one notion: that health is not a suitable major variable for evaluating public fairness, while values, community standards, freedoms, ventures, properties, and primary things are. Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) also acknowledges the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (Couzos & Delaney Thiele, 2007 p. 522).

The above-mentioned studies are an indication that indeed having a child with a disability does have a great influence on parent's quality of life as well as bodily health and such research also suggests the need for the application of Martha Nussbaum's capability approach to assess the capabilities of parents with children with disabilities. To assist parents to accomplish the best bodily and psychological performance, parents of children without disabilities require different resources or have different support needs than parents of children with disabilities. Also, a parent with a physically disabled child may require emotional support (psychologist, counseling) and assistance with the child whereas a parent with a child with no impairment would likely cope with little or no support.

2.4. Combined Capabilities as a Capability

Nussbaum (2020) categorizes capabilities into three kinds which include basic capabilities, internal capabilities, and combined capabilities. She defines basic capabilities as the essential features of a person that are the necessary basis for developing more enhanced capabilities. She further points out that most infants have the basic capability for practical reasons and imagination, though without a good deal more development and education they cannot use it. Internal capabilities are states of persons that are sufficient conditions for the exercise of the corresponding function (given suitable complement of external conditions). Most adults have the internal capabilities of use of speech.

Combined capabilities are defined as internal capabilities plus the external conditions that make the exercise of a function a live option. The study focused more on the combined capability since the aim of public policy is the promotion of combined capabilities and this requires two kinds of efforts (1) the promotion of internal capabilities through education or training and (2) the making available of the external institutional and material conditions (Nussbaum, 2020).

When Nussbaum (2011) talks about combined capabilities, she maintains that combined capabilities are extremely connected to qualities of a person or internal capabilities, as well as personality qualities, intellectual and emotional capacities, conditions of bodily fitness and health, internalized learning, skills of perception and movement. A combination of personal abilities and political, community, and economic settings that support these capabilities are also called combined capabilities, freedoms, or opportunities. Nevertheless, internal capabilities are established in collaboration with the community, monetary, family, and political environments.

Furthermore, Nussbaum (2011, p. 20) added that combined capabilities, or in shorthand ‘capabilities’, are the answer to the question “what is a person able to do and to be?”. “They are not just the abilities residing inside a person but also the freedoms or opportunities created by a combination of personal abilities and the personal, social and economic environment” (Nussbaum, 2011, p.20). For instance, living in a religious society frequently provides a support system facilitating everyday coping.

On the other hand, family beliefs such as seeing the disability as a punishment can also provide negative perceptions of the condition. Religious faith such as the church is often perceived as beneficial for the family’s adaptation since it provides a setting for cognitive and emotional interpretations and processing. Therefore, the government or state aiming to improve human capabilities, must try to better people’s internal capabilities but likewise structure the external surroundings in such a way that boosts the capabilities of individuals (for instance having churches). Therefore, via social policies, the government, according to the capability approach, is eventually responsible for providing the social foundation of these capabilities (Gundersen, 2012).

Nonetheless, parents must play an important role in ensuring that their children’s capabilities are recognized to the uppermost potential point and that their needs are met (Nussbaum, 2006). Combined capabilities can also be limited by “social, political, family, and economic conditions”

that prevent people from performing internal capacities (Nussbaum 2011, p. 30). When parents are deprived of what they see as legally due support to meet documented needs, they may interpret this as a violation not only of their child's dignity but also of their own (Gundersen, 2012).

Additionally, internal capabilities are a person's intellectual and emotional capacities, fitness and health, level of learning skills, etc. Substantial freedom is the ability to make a choice. This ability depends on personal capacities as well as political, social, and economic environments as combined capabilities (Peleg, 2013). Based on this distinction, Nussbaum (2011) argues that if a certain society aims to promote human capabilities, it should support the enhancement of internal capabilities via education resources to improve physical and psychological health, support for family care and love, a structure of education and so forth. This transformation makes it clear how society can facilitate the formation of internal capabilities while decreasing or getting rid of the possibilities of people to function under those capabilities. For instance, people may perhaps be given access to education to improve their capability to voice out what they want to say. Nonetheless if soon after they are denied the right to freedom of expression, for instance, their combined capability is denied too. Society, therefore, should first create internal capabilities to present and produce combined capabilities.

2.5. Conclusion

By using Martha Nussbaum's notion of human capability, it was possible to measure the quality of life of parents with children with disabilities using two central capabilities and combined capability. According to Nussbaum's theory parents of children with disabilities are not able to complete a 'normal' human lifespan; under 'health' and 'bodily integrity' because of the amount of stress linked to their child's disability and care burden resulting in the lack of bodily health and bodily integrity. For that reason, Nussbaum's human capability approach is useful in this instance since it stresses that a life with the absence of any of her ten proposed human capabilities including

bodily health and bodily integrity is not worthy of human dignity. This means that combined capability was highlighted as the capability that takes into consideration parental characteristics of parents with children with disabilities as highly influenced by the social, political, economic, and cultural surroundings. It, therefore, follows that the quality of life of parents with children with disabilities is indirectly affected by their surroundings that in many ways help makes or break them. The social support from the community at large helps parents of children with disabilities cope with the challenges they face in raising their children. It should be noted that the government should ensure that every human being lives a life worthy of human dignity, the same as parents of children with disabilities. The question to ask is whether parents of children are living a life worthy of dignity. Caring for a child with a disability does not only put a strain on a parent's emotions but also has a great impact on their physical health and with assistance from the community and government, the burden can then be eased. Consequently, if the government keeps its obligation in ensuring that parents of children with disabilities benefit fully from all the 10 central capabilities then the human capabilities of children with disabilities will be enhanced. This chapter has presented a theoretical background to the study, reviewed Amartya Sen's capability theory, the underpinning of Martha Nussbaum's human capabilities approach, bodily health, and bodily integrity plus combined capability as a human capability was also further reviewed in the chapter. The following chapter is a literature review chapter.

CHAPTER THREE

LITERATURE REVIEW

3.1. Introduction

This chapter reviews the literature on South African policies and legislation that support parents of children with disabilities. The chapter also discusses the literature on the support system for parents of children with disabilities, early childhood development, and disability, the quality of life of parents or caregivers of children with developmental disabilities, and literature on disability and health care. In addition to this, factors affecting the parental capacity of parents or caregivers of children with disabilities are also reviewed. All these discussions are aimed at highlighting the human capabilities of parents of children with developmental disabilities at the early childhood development stages.

3.2 Defining disability and developmental disability.

According to the International Classification of Functioning, Disability and Health (ICF), disability, consists of the impairments movement restrictions, and engagement restrictions that result from the interaction between a health condition and the affected person's environment (Schiariti et al., 2018). However, the current study centered specifically on developmental disabilities of children 0-8 years. Developmental disabilities are defined as a collection of conditions consequential from impairments that have an impact on the behavior, learning, and body functioning of a child. Children that are affected commonly have impairments in their senses such as loss of vision and hearing, seizures or epilepsy, autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), cerebral palsy, intellectual disability, or other learning disorders. Children with developmental delays and disabilities are at a higher possibility of reduced

levels of health, wellbeing, and accomplishment of education, than are children with no such disabilities (Olusanya, Davis, Wertlieb, Boo, Nair, Halpern & Kassebaum, 2018).

According to WHO (2018), disability is part of human beings and at some point, in their lives, almost every person will experience disability temporarily or permanently. Mitra (2017) well-defined disability as lacking in terms of functioning(s) and/or capability(s) among persons with health deprivations. Disability results from the interaction between resources, personal and structural factors, and health deprivations. Disability classifies a particular type of deprivation or drawback that might be the target of policies. The word is also possibly stigmatizing as persons with disabilities are disadvantaged, and it becomes impossible to put across a neutral or potentially empowering discourse about them. Similarly, Mitra (2017) further added that the notion of disability is puzzling, at the same time vague. The word itself ‘disability’ has negative associations, which is no wonder given the prefix ‘dis’ denoting absence or contrary. Further than the everyday semantic confusion about the word ‘disability, how it is theoretically defined is also complex. Researchers have long argued with the definition, which is important. Disability is defined by the human development model as numerous possible factors that might have an impact on the person’s wellbeing (the personal factors, the resources, and structural factors). Personal factors are individual characteristics. They may consist of simple demographics for instance age, race/ethnicity, and sex. They can also be more multifaceted features such as personality traits. Some are unchallengeable for example date of birth; others can be changed such as personal attitudes. Resources take account of services, personal property, and information. They could be owned by the individual herself or stand for resources that she can have access to through family or community services. Structural factors are broad and cover physical, social, economic, epidemiological, political, and so on characteristics of the person’s setting. Structural factors speak about to characteristics of the person’s direct environment such family, home, and workplace, the meso-environment, which is the community, and the regional, national which is the macro-

environment. Structural factors may influence capabilities and functioning's at each of these levels.

3.3 Children 0-8 years with a disability

The phase before birth up until eight years of age is known as the early childhood period. Early childhood development is also declared as the most life-threatening period of human development and the most important stage of an individual's brain development (WHO, 2018). Health and social consequences are affected by what transpires before birth and in the first few years of a child's life. However, the environment has a most important influence during early childhood, as well as hereditary aspects, also have an impact in shaping children's development (WHO, 2012). A qualitative study by Ben-Zur (1999) distinguished several visible features of parents who have an advanced level of dealing with or with the situation when investigating the day-to-day schedule of families with a developmentally disabled child. The most important element of effective coping for parents raising a developmentally disabled involves reshaping existing undesirable conceptions perceptions and thoughts concerning the set of circumstances, and the capacity to reassess the circumstances. More encouraging brainwaves, which enable healthier ways of dealing with the situation, opening a room of acceptance of the child's current state of disability, the strength of will succeed, and finding an ambition or value for the condition at hand. For families who cope well it is important to find appropriate stability with everyday duties and functions towards other children, significant other, work, and individual needs, at the same time similarly allocating time and resources to bodily and psychological health and growth, in a way that fulfill equally to the necessities of other family members and the child's needs. Efficiency in pursuit of and use of resources was also discovered to be linked to effectual coping, collecting data, collaboration with experts, engaging in support groups available, and developing interaction with other parents. Additionally, it can be anticipated that the more proficient and extensive the family's means before the birth of the disabled child, the easier it will be to adjust and cope proficiently with the new

circumstances, although alongside dealing with other encounters the birth of a disabled child occurs within a very clear context of a certain family structure, at a certain developmental stage (Ben-Zur, 1999).

Out of one billion people living with a disability, about 200 million children globally are estimated to be living with some type of disability. It is additionally revealed that people with disabilities are among the poorest of the poor and do not have comparable opportunities and equal access relating to health, occupation, and education. As a result, their rights are violated even further therefore in low-income countries and those living in the underprivileged quintile of the domain's residents (WHO, 2011). This means that disability is triggered by social disadvantage which might lead to a sequence of inequalities and gaps in health. The reality of the inequalities mainly for children with disabilities are depressing; nearly all the disabled children in developing countries have low literacy levels which is caused by the lack of school attendance resulting in; a third of the world's street children are living with some form of disability and social disregard and inadequate access to social public amenities (Kuwana, 2014).

In South Africa, statistical figures of childhood disability referring to males or females and age prevalence is insufficient, changeable, and often contradictory (ACPF, 2011). One of the main reasons for this is that South Africa does not yet have a universal or generally recognized evaluation instrument aligned with the International Classification of Functioning (ICF). Therefore, child disability prevalence estimations formed from several references are as a result not precisely similar for the reason of various classifications of disability and approaches of data collection (DSD, DWCPD & UNICEF, 2012). After-1994, as soon as the apartheid regime was abolished, the South African government had the duty to establish independent systems as well as liberal legislation and policies to source fair implementation and provision of services. Therefore, South Africans came up with political, social, and economic transformation policies to support the society at large (African Child Policy Forum, 2011). South African government acknowledges that

children with severe disabilities need wide-ranging care and attention and that a parent may hire a caregiver to take care of the child or must stay at home to care for the child themselves. Children with disabilities may need medication, ongoing treatment such as physiotherapy or assistive machines. These additional costs can put pressure on families that are already striving to make ends meet (ACPF, 2011). On that note, Tigere and Makhubele (2019) pointed out that South Africa has one of the greatest policies for children with disabilities, mainly being a signatory to the United Nations Convention on the Rights of the Child (UNCRC) in 1995 and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007.

Research from DSD, DWCPD, and UNICEF, (2012) revealed that South Africa does not thus far have a nationally recognized measuring tool in line with the ICF. Assessments of child disability prevalence created from numerous sources are for that reason not directly similar because of different definitions of disability and methods of data collection. Also, while the census and other national household surveys do consist of common questions about people with disabilities, these questions were not specially designed to detect children with disabilities.

A general household survey conducted by Stats SA (2016) shows that people with disabilities encounter many types of discrimination in various social spheres, including in respect of access to health care services, employment, and education. Also, the beginning of democracy in 1994, in South Africa, indicated a new developmental method to the delivery of social services to all disadvantaged groups in society, including people with disabilities (National Integrated Early Childhood Development Policy, 2015).

The National Disability Policy further indicates that many disabled children are more exposed to exploitation and violence because of their disability and that leads to rejection or exclusion from experiences that are part of the 'normal' development of every child. In most instances, cases of disability are preventable diseases like measles, alcohol and drug abuse, or disability caused by

social and political violence because of poverty. Because of the scarce and inadequate facilities for early discovery, identification, and support in rural areas or informal settlements, children living in these areas are the most exposed to disablement and HIV & AIDS, therefore, leading to a progression in both the extent and the intensity of impairment (NIECDP, 2015).

3.4 Global frameworks and policies for disability

All states should include human rights standards in their national legislation as credited in present international law. From country to country, it will differ the resources of the community, economic and cultural rights of individuals with disabilities that are selected to endorse full attainment. This means that in all the countries the policy or program effort is necessary (Alter, Helfer, & McAllister, (2013). The United Nations (UN) Charter itself identifies important responsibilities of member states to ensure respect for human rights and fundamental freedom for all. There are several universal treaties and recommendations relevant to the rights of persons with disabilities and must be approved under the auspices of several intergovernmental bodies and international agencies. General worldwide and regional human rights instruments consist of the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights and the Social and Cultural Rights, International Covenant on Economics (Enable, 2015).

The UN Sustainable Development Goals (SDGs) were developed based on the standard that people universally are ought to have fair and worldwide access to all stages of quality education, proper health care, and social security, where bodily, mental, and social well-being are secured. Children with developmental delays and cognitive, mental, and neurological disabilities are considered in this vision for inclusive healthy societies (Collins, Pringle, Alexander, Darmstadt, Heymann, Huebner, & Zindel, 2017). For this reason, frameworks like the Global frameworks for development in low and middle-income countries are in place and purely put emphasis on improved access to services for disabled children and their families (Underwood, Angarita, Curran,

Runswick-Cole & Wertlieb,2020). Correspondingly, the 2030 Agenda is established in the Universal Declaration of Human Rights and international human rights treaties and makes it clear that the Sustainable Development Goals cannot be accomplished without respect for human rights.

On the other hand, the UN Convention on the Rights of the Child (CRC) additionally specifies that based on their disability, children with disabilities cannot be left out from free and obligatory primary and secondary schooling. However, children with disabilities are more probable to obtain the poorer lesser amount of healthcare, development services, and early childhood maintenance, and education and are brought up underprivileged. Therefore, caregivers and parents play a central role in assisting children's access to early childhood development interventions, as well as healthcare and education, but must be sufficiently assisted by their states (Collins et al., 2017).

The Nurturing Care Framework (NCF) makes it known that childhood disabilities impose a huge emotional and economic burden on the affected families and children. Noting that caring for children with disabling conditions is demanding, especially in places with inadequate infrastructure and access to services and support. Therefore, families frequently go through many encounters and shortcomings. These include residing in places with poor access to proper quality early identification, lack or absence of transfer to early childhood intervention services, and insufficient assistance for family and caregivers. Caregivers or parents may moreover suffer from the shortage of monetary and economic support which in turn might affect their parenting capabilities.

A study by Olusanya, Davis, Wertlieb, Boo, Nair, Halpern, and Kassebaum (2018) found out that globally, 52,9 million children younger than 5 years had developmental disabilities in 2016 compared with 53,0 million in 1990. About 95% of these children lived in low-income and middle-income countries. Although the prevalence of developmental disabilities among children younger than 5 years decreased in all countries (except for North America) between 1990 and 2016, the

number of children with developmental disabilities increased significantly in sub-Saharan Africa (71,3%) and in North Africa and the Middle East (7,6%). South Asia had the highest prevalence of children with developmental disabilities in 2016 and North America had the lowest.

Based on the above findings, Olusanya et al, 2018 further included that this meant that the global burden of developmental disabilities has not significantly improved since 1990, suggesting inadequate global attention on the developmental potential of children who survived childhood because of child survival programmes, particularly in sub-Saharan Africa and South Asia.

There has been growing recognition in present international law that all states should incorporate human rights standards in their national legislation. Although the means chosen to promote full realization of economic, social, and cultural rights of persons with disabilities will differ from country to country (Alter et al., 2013). The frameworks and policies at national level are further discussed below:

3.4.1 The Charter on Inclusion of Persons with Disabilities in Humanitarian Action

The Charter represents a commitment to render humanitarian action inclusive of persons with disabilities based on five principles: non-discrimination; participation; inclusive policy; inclusive response and services; cooperation and coordination. The Charter was developed at the World Humanitarian Summit in 2016 and was endorsed by over 70 stakeholders from States, UN agencies, the international civil society community, and global, regional, and national organizations of persons with disabilities. This Charter is open for endorsement by States and governments, UN agencies, organizations involved in humanitarian contexts, and organizations of persons with disabilities.

3.4.2 Access to health

Article 25 of the UNCRPD says that it is the right of all people (including children) with disabilities to have the highest standard of health care, without discrimination. While some conditions associated with disability result in poor health and extensive health care needs, others do not. However, all children with disabilities have the same general health care needs as everyone else, and therefore need access to mainstream health care services. For example, children with disabilities should be included in post-natal home-visiting services and clinic visits, and should receive their regular vaccinations and immunizations, along with all children. Furthermore, in adolescence, they should access services for sexual and reproductive health.

Children with disabilities should also have access to specialist health care services such as physiotherapy, occupational therapy, and speech therapy. Children with disabilities can often face barriers in accessing basic and specialist health care. This can be because families cannot understand the complex health needs of their children, do not have the information about available services and resources, or do not acknowledge abilities and access to mainstream health (World Health Organization, 2015).

3.5 South African legislation for disability

As part of South Africa's approach to poverty alleviation, the country is heavily invested in policies intended at ensuring that all members of the population have access to basic services as well as suitable shelter, non-toxic hygiene, and energy sources. The policy is projected not only to meet the Constitutional rights to human dignity but also to safeguard that several basic needs are met through government provision, allowing income to be expended on meeting other household and individual-level needs (Richardson, 2018).

3.5.1 Social Welfare White paper

In supporting the families of children with disabilities in South Africa, the White Paper for Social Welfare expresses South Africa's developmental and inclusive approach to social welfare. The policy seeks to meet people's basic needs and improve their capacity so that all South Africans can accomplish their desires and take part fully in social, economic, and political life. The White Paper outlines an all-inclusive structure of services to make sure that all people have economic and social protection, and access to welfare programmes that encourage growth. The policy also points out that to achieve social growth, social welfare needs to be like other structures such as health care, nutrition, education, housing, employment, leisure, rural and urban improvement, and land transformation (Department of Welfare, 1997, p. 9). Equally important is the White Paper on Families (2012) which intends to encourage inclusive economic development in the country and positive family well-being. The Paper also aims, as one of its main objectives, to enhance the caring, nurturing, socializing, and supporting capabilities of families to allow their members to take part effectively in social growth. As approaches to support families and promote family life and development of each family member, parenting support is encouraged (NIECDP, 2015).

The Social Welfare White Paper emphasizes the developmental importance of targeted programmes including cash transfers and services to ensure that people have adequate economic and social protection during times of unemployment, ill-health, maternity, child-rearing, disability, or old age. "Social welfare programmes of this nature contribute to human resource development by enabling impoverished households to provide adequate care for their members, especially children and those who are vulnerable. Despite the progress made in terms of legislative and policy reform, the realities for children with disabilities have not changed much (ACPF, 2011). Indeed, the department of social development acknowledges that "... services to children with disabilities remain fragmented and unequal. Government departments still work in silos and services are not

coordinated. Systems to identify children with disabilities at birth and track their progress through early childhood on to school-going age are sadly deficient” (DSD, 2009, p. 9)

Similarly, the National Development Plan (NDP), the White Paper places huge importance on the family, which is regarded as a fundamental element of society. It claims for the development and delivery of a multi-sectoral suite of services and support for families to enable them to provide adequate care for their members, especially children, and in so doing so free them from apartheid’s legacy of poverty and inequality. This integrated approach is seen as essential for addressing the structural drivers of poverty and inequality (Department of Social Development, 2016, p. 29).

3.5.2. National Integrated Early Childhood Development Policy

According to the National Integrated Early Childhood Development Policy (2015), the government is delegated and compelled to make sure that the running of early childhood development services is a right. They must be delivered publicly because they afford a basis for good child outcomes as well as national developmental outcomes are required to make equal the developmental shortfalls experienced by infants and young children exposed to risk factors and as a result, are necessary to attend to South Africa’s two key development challenges which are poverty and inequality. As mentioned in the National Integrated Early Childhood Development Policy (NIECDP) 2015, of the Republic of South African, Government acknowledges that the child’s parents are responsible and vital for his or her care, development, and well-being by providing a nurturing and caring environment during the crucial early years of life. Above all, the Government acknowledges that parents and other primary caregivers are ought to have access to and receive the information, support, and services required to allow them to undertake their parental responsibilities. For that reason, early childhood development relies on effective measures to safeguard not only children’s rights but those of their parents, given that this affects the capacity of parents to ensure their children’s complete and most favorable development. Over and above

acknowledging early childhood development as a universal human right, Government acknowledges early childhood development as central to the understanding of the national development goals of lowering poverty and inequality (NIECDP, 2015).

It is evident in the ACPF (2011) that children with disabilities in Africa are amongst the excluded groups both in the policy section and the private domain. The majority of these children encounter huge economic, political, and community barriers that have an impact on their physical, community, welfare, and psychological development. Access to basic needs such as health services and education are some of the multiple deprivations these children also tend to experience even within their families and are invisible in the national policy agenda. As a result, this affects the lives of parents raising children in these conditions.

To assist families to care for their children and to support children with disabilities and their parents a variety of policies, laws, and programmes have been implemented and put out to offer worldwide services (NIECDP, 2015). For instance, the National Health Act No. 60 of 2003 (effective from 2005), aims to regulate national health and to offer equal health services around the country. The Act also strives to protect the rights of vulnerable groups and means to pay attention to, safeguard, encourage, and meet children's right to basic nutrition. It requires the state to offer 'health services' and consist of 'basic nutrition included in the definition of health services.

The National Integrated Early Childhood Development Policy is relevant to the study because it is intended at enhancing early childhood development service delivery in South Africa, to address serious gaps such as parenting or family support and social security, and to make sure that service delivery is all-inclusive, universally accessible so the parental capacity of parents with children with disabilities may be assisted and help ease the caregiving burden to parents.

3.5.3. Social Assistance Act No.13 of 2004

In addition to these policies is the Social Assistance Act No.13 of 2004, which provides non-contributory cash transfer programmes focusing on those with disabilities needing permanent care or support services (the Care Dependency Grant) and the South African Social Security Agency (SASSA), and appropriate children living in poverty, working together with the Department of Social Development (DSD), is the lawful body accountable for the delivery of these social assistance programs to all suitable children. The Department of Social Development has the main responsibility for the operation of the Social Assistance Act.

Consequently, the provision of support to families by the state is important to achieving sustainable development. Families are recognized by human rights and development structures as key development partners, with whom children's rights and lasting development cannot be achieved without. If the policies and programmes in place recognize and value the diversity of family arrangements and are responsive to families' changing needs, supporting families makes a difference. To ensure that no child is left behind, states must develop policies, laws, and programmes that are inclusive of all families, such policies must promote children's rights and development structures. Therefore, a suitable degree of economic security, access to resources and basic services including health, nutrition, and education, and safeguard from violence to be capable to act on behalf of themselves and their children is needed for parents or caregivers of children with disabilities (ACPF, 2011).

Access to social services such as support and assistance services, child protection systems, and social welfare services and benefits is required for children with disabilities and their family members. Barriers to security and essential social services such as disability are recognized as inclusive social protection because of the social dimensions of exclusion. This means that in instances where families of children with disabilities face financial and social barriers to access

basic and essential services, social protection programmes are there to support them. These programs consist of the use of current social transfers such as provisional cash transfers; anti-discriminatory legislation; and policy improvement (Republic of South Africa, 2015).

3.5.4. Children's Amendment Act

Partial care programs are there to place and assist children with disabilities without the assistance of their families (NIECDP, 2015). In terms of the Children's Amendment Act, partial care is a service obtainable during the day or night care for up to more than six children, along with those with disabilities, on behalf of their parents with or without any payment for a short-term period. Children with disabilities who can do things for themselves should be included in the mainstream partial care facilities (NIECDP, 2015). The needs of children with disabilities should be considered by employing all the standards and values for partial care facilities, for instance, children with a communication or hearing disability need staff members to know basic sign language. Training should be afforded to the service providers that will allow them to take care of and include children with disabilities in the stimulation programmes (Integrated National Strategy on Support Services to Children with Disabilities Revised Draft, 2009).

3.5.5. Children's Act - Right to a standard of living and to benefit from social security.

One of the special objectives represented in the Act is "to develop appropriate parenting skills and the capacity of parents and caregivers to safeguard the best interests of children with disability" (Clause 144 1 (c)). As mentioned above, children with disabilities are frequently found to be malnourished, deserted, or not able to take part fully in family and community life. The right to a considerate standard of living for children with disabilities recommends bettering their quality of life, and as a result, creates a challenge to change the current circumstances for all children with a disability in South Africa. Different types of social grants are provided for through the Social Assistance Act in support of this Act, these socials grants include the Care Dependency Grant

(CDG) that is aimed specifically at children with disabilities; the Foster Care Grant or the Social Relief of Distress is additionally provided for children with disabilities (Integrated National Strategy on Support Services to Children with Disabilities Revised Draft, 2009). As mentioned by ACPF (2011) that the Social Assistance Act offers for the care dependency grant, a non-contributory monthly cash transfer for parents, foster parents, or primary carers of “a child who needs and receives permanent care or support services due to his or her physical or mental disability” (RSA 2004 clause 7a).

3.5.6 Policy implementation problems in South Africa

The rate of service delivery is challenged by the insufficient placement of policies to strategies of Departments. Several policies are available that are anticipated at achieving the legal and lawful commitments of the government concerning children with disabilities (DSD, DWCPD & UNICEF, 2011). In the review of the influence of disability policy implementation in South Africa et al., (2008, p. 26) discovered that “the main obstacles to the application of the Constitution were negative attitudes towards disability, prejudice, misconceptions about disability issues and stereotyping”. Wildman and Nomdo (2007) also discovered the main factors for the lack of implementation of policies such as the lack of budgeting for services for children with disabilities, lack of implementation of services such as rehabilitation and assistive devices. The Department of Basic Education (2012) discovered that insufficient information gathering structures make it difficult to follow actual development with regard to enrolment trends amongst mainstream and special schools.

For that reason, *“children with disabilities continue to experience discrimination at all levels of society. They are excluded from mainstream services that are relatively more resourced, less costly, and within reach. These services are not accessible due to physical structures,*

communication barriers, negative attitudes, and inexperienced service providers” (DSD, 2009, p.11).

Consequently, “children with disabilities remain mostly marginalized and particularly vulnerable to negative social attitudes. Rejection of informative years for young children has a significant role to play in the exclusion from normal development of a child and participation in family and community life. Children with disabilities are excluded from mainstream services and cannot function optimally, not only because of their disabilities but also due to inaccessible buildings, attitudes of service providers, and the community” (DSD, 2009, p.16).

Regardless of the evidence provided, not much has been done to confront the rights of children with disabilities that are violated via the presently obtainable channels (ACPF, 2011), in turn, this, therefore, places parents of disabled children at the challenge in matter of ensuring that the needs of their children are met.

3.6. Caring for children with a disability

Care is defined as a steady environment that protects from harm, opportunities for early learning, and interactions that are responsive, emotionally caring, and enhancing developmentally and that are sensitive to dietary needs and children’s health. These environments offer acceptance and a sense of belonging and connection demonstrated through an active and constant relationship with the child or adolescent (Berry and Malek, 2017). Caregiving or providing care involves assisting another person to perform such activities for an individual who is not capable to do them, perform tasks which are needed for survival, human functioning, or involvement in the society (National Academies of Sciences, Engineering, and Medicine, 2016). A child with a disability frequently needs caregiving through life and in adulthood (Muller-Kluits and Slabbert (2018).

Berry and Malek (2017) indicated that healthy, caring relationships can be impacted by several factors the development. It is critical that a caregiver is emotionally available and connected, showing concern and attention via frequent, meaningful relations despite the fact a caregiver may be present in a child's life. Responding with sensitivity to the child's needs places the child at the center of these engagements and allowing the child to be in the lead of these relations. The responses of a caregiver are affected by the child's behavior and character, childhood experiences, parent's character, and parenting style. Additional influences that impact the caregiver's capability to provide sincere, responsive caregiving consist of the caregiver's physical and mental health, stress exposure, coping mechanisms, and the availability of assistance and resources for assistance.

Health is an important additional feature of the capabilities approach and is a significant result of development interventions, along with other results. Like education, health is very significant in the capability's framework that, it is one of the key measures contained within the Human Development Index in the procedure of 'Life Expectancy'. In South Africa, it is well recognized that people with disabilities are less likely to have suitable access to health care services and health information (Eide et al., 2011). However, the relationship between health conditions and disabilities is difficult to understand as several environmental and demographic factors need to be considered. This consequently has a great influence or challenges the parental capacity of parents or caregivers or children with disabilities (ACPF, 2011).

An example of the impact of caregiving on the health and well-being of caregivers is demonstrated on the caregiving stress process model below:

3.6.1 Parent or caregiver background/context

Caregiving does not occur in separation from one's past and current community or, thus it must be considered within this context (Schulz & Eden, 2016). The concept of background/context is incorporated to focus on the setting in which caregiving takes place, highlighting the economic

and social characteristics of the family. In other words, socioeconomic resources might be of assistance to hold the level to which a patient's condition becomes burdensome and socioeconomic variables have appeared as main relations of exposure to care-related stressors. A socioeconomic status factor can be established employing measures of parent's education, employment status, and profits family (Muller-Kluits & Slabbert, 2018). For families with major disabled children meeting their basic requirements has additional costs. As a result, most families with a disabled child have expressively lesser earnings than other comparable families. Too little salary is a basis of anxiety for parents, and it also stops them from getting other incomes such as obtaining a house or childcare assistance (Schulz & Eden, 2016).

The background of the parent consists of community-level means, policies, situations, and traditions that have an impact on a community's health insights and the existing state of affairs (Karimi & Brazier, 2016). It is vital that stable income, safety from violence and the ability to act for themselves and their children, the opportunity to make use of resources and basic services available, access to food, and proper education for caregivers or parents of children with disabilities.

Malhotra et al., (2012) suggest that when clarifying the quality of life (QoL) of parents or caregivers the most significant feature to consider is caregiving and its related responsibility. Family caregivers function as an additional room of healthcare systems (carrying out all-around medical and therapeutic responsibilities and encouraging compliance to the therapeutic programmes) though, they frequently do not have suitable skills, training, or constant support from these structures. Therefore, when parents or caregivers lack education, assistance, and provision, affects their bodily and psychological health, and their economic means their caregiving duties can be negatively affected (Muller-Kluits & Slabbert, 2018).

Moreover, the extreme degree of care associated with caring for a child with a disability, has an impact on parents' psychological health thus, impact negative rehabilitation results in their children (Hung et al., 2010). For overall management, parents need to be consistent and participate fully throughout all stages of treatment of children with developmental or bodily disabilities. Nevertheless, parents' bodily and psychological health may be affected by the excessive amount of work done when taking care of a child with long-term functional restrictions (National Academies of Sciences, Engineering & Medicine, 2016). Additionally, parents' role of supervision of the child's ill health might be restricted when a parent experiences physical complications such as fatigue (Lindo et al., 2016). The National Academies of Sciences, Engineering & Medicine (2016) further noted the disability might have a huge effect on the family therefore family's capability to deal with the disability; is the result of the emotional and psychiatric distress to the child which may be caused by parents' emotional distress.

When comparing children without disabilities and those with disabilities and their families evidence suggests that those with disabilities are more likely to be subjected to difficulty economically and socially (WHO, 2012). This suggests that families of a person with disabilities tend to be poor leading to poor health (Geere et al., 2013). Because of the amount of care required by a child with a disability parents take time away from income-generating activities, therefore, families are compelled to meet the extra expenses linked with a disability, for instance, costs for transport and disability health care resulting in multiplied poverty at the family level (WHO, 2012).

Likewise, poverty is strongly connected to disability, while any family can be affected by disability, the likelihood of disability may increase by poverty and may also be a result of disability (Eide & Ingstad, 2013). Poverty can have a direct effect on the fetal development of pregnant women living in poverty as they may go through deprived health, limited food, and exposure to environmental toxins and contaminants. When comparing children from higher socio-economic backgrounds and those living in poverty it has been found that those living in poverty are more

likely to experience developmental delays because they are excessively subjected to a variety of dangers (Ross & Deverell, 2010). These consist of insufficient nourishment; inadequate hygiene and hygiene; vulnerability to violence; absence of access to improved health services; poor housing; more motherly pressure and sadness; vulnerable to diseases and sickness, exploitation, and negligence; poor skills to care for children; and insufficient motivation (Ross & Deverell, 2010).

On the other hand, most societies hold negative ways of thinking, and opinions regarding disability resulting in parents or caregivers feeling isolated. These parents may live through poverty because of the lack of needed economic support, limited community support, inadequate contact to information required to provide suitable maintenance for their children (WHO, 2012). Most of these encounters cut across disability type, age of the person with the disability, and type of family in which the person lives (Muller-Kluits et al., 2018). It has been indicated by the National Academies of Sciences, Engineering, and Medicine (2016) that the government also recognizes that parents might be required to stay at home full-time or hire someone to care for the child because children with serious disabilities required huge maintenance and consideration such as regular healthcare such as physiotherapy, machines to assist, or treatment. For families that are already finding it hard to survive or cope, extra strain or burden will be felt when it comes to the health care maintenance for the child (Hall, 2009). As previously mentioned, Van der Mark et al., (2019) also highlights that the parents of children with disabilities are not only affected psychologically but also face a physical weight, caused by issues such as lack of sleep, the obligation of carrying the child in cases of children that cannot do things themselves, and stress. Because of this, headaches, exhaustion, and muscular ache are frequent with caregivers. Furthermore, parents of children with developmental disabilities are themselves disabled, by the feature of their given tasks and responsibilities as caregivers of developmentally disabled children.

A study by Dardas and Ahmad (2014) titled “Psychosocial correlates of parenting a child with Autistic Disorder” investigated a sample of parents of children with autism spectrum disorder (ASD) to explore the relationship between two groups of variables. The first group was made of the parents’ features. The second group was made of three stress subscales parental distress, parent-child dysfunctional interaction, difficult child, and the parental quality of life. Canonical correlation multivariate analysis was employed in the study to explore the link amongst the groups of variables in 184 parents of children with an autistic disorder of Jordan. The study outcomes revealed that the parents who earn higher salaries, make use of different assistive replacement approaches for a solution, display a lesser amount of escape avoidance, and display a smaller amount of accountability acceptance behavior as a result reporting lesser parental distress, parent-child dysfunctional interaction, and fewer results of a difficult child, and advanced quality of life outcome. The analyses further discovered that lower parental distress results, higher parent-child dysfunctional interaction and difficult child results, and better quality of life were linked with being a more mature parent and employing more coping strategies.

An additional international study by Seltzer and Greenberg (2001) investigated “Life course impacts of parenting a child with a disability”. Wisconsin longitudinal study was employed in the study. The outcomes of the study revealed that parents of a child with a developmental disability are mostly unemployed, have bigger families, and often participate less in social activities but were comparable to parents without a child with a disability in marital status and educational position, mental welfare, and bodily well-being.

However, research that was done by Smith and Grzywacz, (2014) specified that community support promotes positive adjustment on individuals subjected to burdensome conditions since most parents or caregivers raising a child with special health needs frequently report inadequate supports and feelings of vulnerability. The WHO (2012) indicated that when promoting the development, education, and progress of children, it is important to improve household settings

and relations to accommodate the needs of the child. These are important because when a child has a disability the quality of the relationship between the child and caregiver might be affected (WHO, 2012). It has been further indicated that many investigations have revealed that when a child has a disability the interaction between a child and parents is mostly different from one of the carers of children with no disability, a child without a disability, parents, or caregivers of children with disabilities commonly administer connections more than parents or carers of children with no disability (Algood et al., 2013).

Additionally, Lindo et al., (2016) mentioned that all parts of interactions and relationships within the family can be influenced by the part of the encounter of living with a child with a developmental disorder, in both good and bad manner. Possible good results observed in the studies done consist of improved internal power, flexibility, unity, and connection with the society. On the other hand, focusing on difficulties and complications risks, neglecting the pleasure and fulfillment that can occur from raising or caring for a disabled child. Parents and siblings of children with disabilities frequently love and appreciated them, and mothers in specific might obtain a lot of extra abilities and competencies during their caring roles (WHO, 2012). Likewise, a systematic review is done by Hohlfeld et al., (2018) that aimed at evaluating the usefulness of parenting interventions to boost parents' level of beliefs about their capabilities to take care of children with developmental disabilities revealed that indeed, training programmes for parents lead to an increase in numbers in parental self-efficacy levels. The study further revealed that after parenting interventions, parents of children below the age of 5 years displayed the greatest growth in degrees of parents' beliefs about their capabilities to take care of children. Additionally, the review indicated that to improve parenting self-efficacy training programmes carried out by medical care experts and psychologists are indeed helpful. National Academies of Sciences, Engineering, and Medicine (2016), indicates that the most important people in the lives of little children are primary caregivers or parents. From day one, a child is dependent on their primary

caregivers or parents along with other people, to map a route that encourages their complete welfare and to protect and care for the child. Even though parents generally are filled with hope about their children's developing personalities, many also do not have proper information on how to take care of their children in the best possible way. National Academies of Sciences, Engineering, and Medicine (2016) further state that becoming a parent is usually an event to be pleased for, but in some cases where a child has a disability, lives of parents are on edge with difficulties and doubt concerning their capability to safeguard their child's bodily, psychological, or financial welfare. It has been noted that caregivers commonly identify that they have taken away their own basic personal needs and to accommodate the special needs of the child, for instance, a suitable night's sleep or creating the time for good, nourishment (Mörelus & Hemmingsson, 2013).

3.6.2 Child characteristics of a child with a developmental disability

The child characteristics concept specifically refers to indicators of the child's disability and therefore signify actual care demands and thus, speak to factors that are real conditions of caregiving (Toledano-Toledano & Domínguez-Guedea, 2019). The research has pointed to the disability of the child and child behavior problems as main influences linked with caregiver health (Fisher, 2019). The behavior of young children with disabilities often creates great stress for the parents and poses challenges which therefore gives rise to negative parent-child interaction (Hastings, 2002). It is therefore important to encourage parenting practices associated with behavior management diversity of approaches have been put forward. To mention one is the multi-component program which involves problem-behavior prevention strategies and intensifying levels of behavioral intervention such as support and approach positive behavior intervention (National Academies of Sciences, Engineering & Medicine, 2016).

The quality of parenting is reflected in an adult's ability to identify and adequately provide for the child, in a developmentally and emotionally appropriate manner, a child's current and anticipated needs (Fisher, 2019). Suitable parenting is flexible enough to adapt to changeability in those needs, and the particular child's selection of responsiveness, in the situation of their social environment (Cleaver & Unell, 2011). However, factors both in the child and in the environment shape the quality of parenting, the important determinant of the experience for the child is invested within the parent and is defined as parenting capacity (Fisher, 2019).

Parents must develop both complex and extensive knowledge to meet the diverse needs of their children, varying from being observant of developmental signs and standards that assist in keeping children safe and healthy and understanding the duty of professionals such as educators, childcare workers, health care providers, social workers and social systems that consists of institutions, laws, policies that work together with families and encourage parenting (Gadsden et al., 2016). Muller-Kluits & Slabbert (2018) mentioned that therapy and equipment to assist in caregiving and mobility for people with disabilities are therefore often difficult to access, particularly for poor people and those living in remote or rural areas. Lack of access to assistive equipment may mean that caregiving in low-income countries requires more physical work and manual handling than it does in high-income countries and thus is associated with a greater risk of injuries or physical health disorders.

3.6.3 Caregiver strain

Factors considered under this construct are caregiving demands and perception of formal care. Caregiving demands measure the daily demands on the caregiver, as well as conflict between the caregiving role and occupational roles of the primary caregiver.

Caregiver strain can also consider the amounts of bodily work that are included in caring for a child with a disability, a different amount of assistance is required depending on the child's extent

of disability and available resources (Geere et al., 2013). For instance, bodily work may be important to support a child with social movement, sit down, or body movements, as well as for putting on clothes, bathing, feeding and giving them drinks. Physical work can equally influence bodily health hence the need for assistance on the available community resources (Geere et al., 2013).

Therefore, the Bill of Rights contained in Chapter 2 of the Constitution of the Republic of South Africa (1996) Section 28, recognizes care, concerning a child, consist of, where suitable (a) with resources available, giving the child - (i) an appropriate home to stay; (ii) living circumstances that are favorable to the child's health, development, and welfare; and (iii) the monetary assistance required; (b) promoting and safeguarding the well-being of the child.

The World Health Organization (WHO, 2012) describes health as not just the absence of disease or illness but a view of absolute bodily, psychological, and communal welfare. Health-related quality of life (HRQL) emphasizes a person's health as the effect of on capability to live a satisfying life. HRQL embodies a broad notion of physical, psychological with social functioning and well-being that consists of both good and bad viewpoints (Karimi & Brazier, 2016). Correspondingly, Malhotra et al., (2012) included that quality of life (QOL) is complete overall well-being that consists of a combination of fact-based descriptors and individual valuations of bodily, factual, communal, and psychological welfare, this comprises health, contentment, and a fulfilling job, formal training or qualification, community and academic achievements, freedom to do and to say what you want. When discussing the quality of life, it will be mostly referring to the physical well-being physical which contains health, sleep, pain due to heavy lifting, and coping with the everyday life of parents with children with disabilities.

3.6.4 Caregiver intrapsychic factors

The caregiver's internal state is the focal point of the Intrapsychic factors. For most individuals, caregiving amounts to a new social role, identification with the role often matches with role responsibility and with the development of self-evaluation of how well one performs the role. Self-perception is therefore contemplated as an important intrapsychic factor. Self-perception can be indicated with measures of the caregiver's self-esteem and sense of mastery over the caregiving situation (Muller-Kluits & Slabbert (2018).

A study by Adams et al., (2017) explored how coping strategies used by mothers of children posing challenging behavior correlate to positive and negative maternal mental health. Outcomes from the study showed that coping methods were linked with parental mental health rather than linked with a child's capability or stage of development. Therefore, an enhanced positive effect was linked with enhanced levels of problem-solving skills and positive coping methods. Avoidance coping was found to be the least commonly reported in the study and was consequently linked with intensified worry and unhappiness and increased levels of depressing effect.

Salceanu and Luminita, (2020) pointed out that there are certainly healthy parents who react accurately to a state in which they must live with a disabled child. These parents are those that are willing to reach the stage of acceptance and willfully adjust to their child to facilitate the child's rehabilitation and development, the child's actual situation in this instance is accepted and the problem is acknowledged. If the sense of balance between too many hopes is not reached this might lead to frustrations, and distress therefore it is important to create an ultimate change in approach. Whatever the disability it is, it is very significant to have basic faith in the child's potential. Parents need to learn to appreciate their inner strength to deal with the disability and consider alternate resolutions. They must learn to understand the heart of the disability and the boundaries within which the child may develop to independence. They learn to use the available communal facilities or services and gain from them. Parents usually utilize the assistance of professionals and therapists for this purpose (Salceanu & Luminita, 2020).

3.6.5 Coping/supportive factors

Coping/supporting factors relates to any form of assistance the parents receive whether within the family, the community or by the government structures. Community support takes into consideration the informal assistance received from the social relationships of the caregiver with family, friends, and neighbouring people to manage the situation. (Hohlfeld et al., 2018).

The support provided to families by the broader surroundings where they live is very significant, likewise, parenting is unquestionably crucial to young people's development. Therefore, all families need certain support, for instance, monetary assistance and access to basic health care and education, to fulfill the major responsibilities of taking care of children; some may benefit from more focused parenting support, like parenting programmes for instance (Ward et al., 2015). Transforming attitudes regarding children with disabilities is a continuing problem. When observing this challenge, it has been identified as important to give the needed support to parents, caregivers, and community members who play a role in the lives of their children with disabilities (Philpott & McLaren, 2011). The support for children must include tracing child-development achievement, educating self-governing characters, and caring (Philpott & McLaren, 2011).

The level of education of parents and children must be taken into consideration when distributing disability information must be in diverse layouts and methods. Also, awareness programmes are the important aspects of community structure and should include disability and diversity to reduce the vulnerability of children with disabilities to abuse and neglect (DSD, DWCPD & UNICEF, 2012).

It has been put forward by Kandel and Merrick (2007) that during and after the diagnosis of the child's disability, professional and any form of support systems received for instance friends, extended family, neighbors, support group, and others have a huge substantial place in a family dealing with taking care of a developmentally disabled child. The earlier the diagnosis the more it

is easier for the family members to function through their life cycle when the support is provided to the family. Parents can get chances to share experiences and encourage peer support and encouragement via interventions such as group talks, face-to-face listening, support groups for parents of children with similar disabilities. Promoting suitable activities that caregivers and children with disabilities can do together to improve developmental consequences in children with disabilities is important (WHO, 2012).

A study by Scorgie et al., (1996) identified six key abilities on an investigation of the personality traits characteristic of resourcefully coping with parents and those abilities included being flexible as a parent, being tolerant, being determined, being positive and optimistic approach, sense of humor, and agree to get help when required. A qualitative research method was employed for the study. Findings of the study indicated that competent resourceful coping was related to parents' feeling of control of the situation parents specified that an important element of effectual life management was the capability to live with a certain lack of control over daily life and the future. This may lead to the conclusion that improving and reinforcing a family's range of strengths, including coping strategies, might provide wide support to families with developmentally disabled children.

Also, center-based support and home visits by community workers can be a good way to involve others and to build up the capabilities and self-confidence of parents in supporting the development of children with disabilities. Likewise, caregiving capabilities can also be enhanced by offering educational and literacy opportunities for adolescent girls and mothers (WHO, 2012). Developmental delays can be detected in time when employing methods such as center-based programmes and parenting interventions, including home visiting programmes which in turn may benefit parents and experts to identify and, improve children's development, avoid neglect and abuse, and make sure that the child is ready for school (WHO, 2012). Therefore, support networks benefit the families in several ways, for example, providing emotional and material support

including assistance with necessary tools, reducing stressful situations within the family and throughout the family's life span, guidance, dealing with problems, and mediation, and mainly the structure and uphold a social structure that surrounds the disabled child and the family (Kandel & Merrick, 2007).

This is further pointed out by the WHO (2018) which mentioned the effectiveness of training programmes for families of children with disabilities by enhancing caregivers' skills. These programmes have the intention to develop caregivers' ability to communicate with the child, play interactions, and arrangements at home. These programmes also attempt to develop caregivers' self-confidence in managing challenging behaviors, to know more about their child's state, and intensify their problem-solving and coping approaches. Based on children's and families' needs other elements can also be added to the programmes.

It is widely known that parents have an important role to play in a child's psychosocial development (Kagan, 1999). Therefore, over the past few years, numerous parenting interventions for families of young children with disabilities have been established and evaluated worldwide (Kaminski et al., 2008). The main intention of these interventions is to influence the parent's psychosocial well-being, they are also intended at improving parent's ability to successfully parent their children, by supporting, and educating, or offering them training (Mejia et al., 2012). In a nutshell, the primary intentions of these interventions are to reduce the impact of the challenges faced by the family of children with disabilities by teaching parents new information and abilities to reduce the child's psychological, behavioral, and developmental challenges (Hohlfeld et al., 2018).

As mentioned in the previous chapter, the South African government has a Social Assistance Act that offers monthly cash transfers for parents, the care dependency grant, primary carers, or foster parents of children with disabilities as a way of supporting parents of children with disabilities. To

qualify, the child is obligated to undergo a medical assessment and the parent or caregiver must pass an income or means test. Substantially, the grant can be paid to caregivers, not only parents and foster parents. Any caregiver of a disabled child is eligible, as well as members of the extended family (ACPF, 2011). It has been noted that a close child-caregiver bond is important for both children with and without disabilities therefore, families are important to the development and protection of their children. The home environment is where inclusion begins throughout the early years and later develops to the surrounding influences such as community and school settings (WHO, 2012).

The following are two mini examples of support programs for parents of children with disabilities in assisting them to cope effectively with the challenges that they face with regards to their children's disability.

WHO, (2018) also mentioned that in primary health care at the community level, early family interventions are significant and focusing energies on building up capacities for appropriate detection and interventions. A systems approach of the family systems programs commonly emphasizes parents' internal changes, for example, anxiety, unhappiness, or coping, the quality of parenting is affected by the assumption that transforms in those internal changes. Therefore, these programs are there to provide opportunities for parents of children with disabilities or developmental delays to gather and share shared experiences and worries (National Academies of Sciences, Engineering & Medicine, 2016).

As indicated by the Integrated National Strategy on Support Services to Children with Disabilities Revised Draft (2009), if possible, to function as best as possible within society children with disabilities and their families need access to community programmes of life skills training and confidence-building. Community-based poverty relief programs and other methods of support such as interval care services or assistance from other families must be suggested or referred to

parents of children with severe and intense disabilities. Hence the need for parental programs to support the families to manage the encounters they face is continuous (National Academies of Sciences, Engineering & Medicine, 2016).

3.6.6 Outcomes

Psychological health and physical health are the two health outcomes represented in the model. Health-related quality of life on the individual level consists of bodily and psychological health, insights such as level of strength or feelings and their links as well as health dangers and circumstances, socioeconomic level, communal provision, and working status (Karimi & Brazier, 2016). Physical health has been defined by (Geere et al., 2013) as that relating largely to bodily performance as contrasting to cognitive or mental performance, bodily competence for actions or tasks, and physical pain. The well-being and welfare of the child with disabilities are directly influenced by the health of a primary caregiver (Geere et al., 2013). Taking care of or ‘caregiving’ includes supporting another individual to complete activities that are essential for existence, individual performance, or taking part socially, or doing tasks for a person who is incapable of doing them (Geere et al., 2013). The experiences of parents of children with no developmental challenge are not like the experiences of parents of children with developmental disabilities experience and family members (Woodman, 2014). After the birth of a child with multiple disabilities in a family or when parents are made aware of the diagnosis of their child’s disability, they commonly experience a range of feelings such as pain, rage, or disbelief that are to some extent similar to those felt after hearing about the passing of a loved one. Parents and caregivers may be affected as they may undergo psychological comebacks as they need time to adapt to the new developments (National Academies of Sciences, Engineering & Medicine, 2016). Thus, a shared result in the data is that parents of children with disabilities experience added pressure than parents of children without disabilities but families of young children with disabilities are affected in diverse ways (Woodman, 2014).

Research has focused on the physical health of mothers of children with disabilities and the mental health of parents with children who have disabilities. Physical and psychological health that result in negative physical health for parents of children with disabilities was reported in the following different studies using different measures. Smith and Grzywacz (2014) point out that being a parent to a child with disability needs might challenge parents' bodily health results. As highlighted by Malhotra et al., (2012) that parents of children with different or types of developmental disabilities encounter intensified exhaustion or overtiredness, overload, and marginalization in the public sense of disapproval. For instance, when comparing caregivers of children with long-lasting health conditions and those who do not need to physically support their children, parents, and caregivers of children with physical disabilities who need support with movements have been discovered to have a more frequent body and backbone ache and decreased bodily functioning (Geere et al., 2013). This was made evident by a study conducted by Muller-Kluits & Slabbert (2018) that aimed at exploring and describing the caregiver load encountered by household caregivers looking after a person with bodily disabilities. The study employed a qualitative research methodology to achieve its aim. The findings of the study revealed that many parents' or caregivers' time and energy was provided in looking after their children and additional family members and that caregivers have a habit of prioritizing the health of their children at the expense of their health. As a result, they experience chronic exhaustion and sleep deprivation. The study also made a point that caregivers experience single or multiple long-lasting bodily complaints that they link precisely to the continuing consequences of caring for their children and included that parents' bodily health would similarly be affected by influences like deprived or insufficient sleep, higher risk of hypertension, arthritis, intensified headaches, and greater levels of infection.

Another study by Lindo et al., (2016) further added that that living with the constant strain frequently encountered by parents of developmentally disabled children has been found to have bodily effects on the body and may cause these parents' tendency to take part in behaviors that are

toxic to their well-being (for instance, smoking, unable to get enough rest, and drinking). As a result, constant subjection to higher levels of such toxic health can have a multiplicity of harmful consequences on a person's bodily health, as well as higher blood pressure and impaired cognitive and thyroid function. Therefore, it is of vital importance to identify in time parents who are in danger of poor psychological health because interventions focused on caregivers are likely to be more effective if they focus on changeable elements of parenting responsibilities and tackle parental desires (Da Paz & Wallander, 2016).

Similarly, a study by Mörelius and Hemmingsson (2013) examined whether alleged parental health, headache, and mental fatigue, pain caused by heavy lifting, insomnia, and sleep disturbances are linked with sleep difficulties and attention needed at night amongst children with bodily disabilities. The study made use of a questionnaire about parent's health of 377 children aged 1–16 years with bodily disabilities. All the children lived in their homes with both parents. Outcomes of the study pointed out that both parents presented symptoms of an unhealthy lifestyle, emotional fatigue, insomnia, when the child has sleep problems, caregivers also encounter sleep disturbances. It was also found that when the child had sleep problems mothers also reported more headaches. When the child required attention in the middle of the night, both parents conveyed more sleep disturbances and sleepless nights. It has been documented that; mothers are mostly affected by the above-mentioned poor health symptoms as compared to fathers since they are the immediate caregivers of children.

Moreover, a study by Ha et al., 2012 examined parents' mental and physical health among African Americans urban dwelling with a disabled child, and the study results revealed that certainly poorer mental health outcomes are linked with having a child with a disability. However, when parents receive greater positive support from the family the undesirable effects of the child's disability on parents' psychological health are decreased. As a result, Lindo et al., (2016) noted that when comparing parents of individuals without a developmental disability and parents of individuals

with a disability, it has been found out that exposure to psychological and consistent physiological stressors leaves those parents of individuals with a disability are more exposed to poorer health effects.

Most former studies done focused mainly on either physical and psychological effects or encounters of parents of children with disabilities. There is no evidence that the study focused on the physical well-being of having a child with a disability. Therefore, the data for this study emphasized the physical well-being of parents or caregivers raising a child with a developmental disability.

3.7 Parental care

All human beings begin their lives as helpless children and dependent on the care of others for their survival (National Integrated Early Childhood Development Policy, 2015). Care is essential to our existence as people and communities, along with our dignity and our happiness (Kolm, 2019). Conversely, care alone is not enough simply because people also need suitable food, shelter, and access to other resources and opportunities that make life worth living (Leahy, 2010). Throughout the early stages of life, most human beings face periods of intense dependency; and some human beings continue to be dependent on the daily bodily care of others throughout their lives. Of course, putting it this way suggests, that abled-bodied human beings do not depend on others for bodily care and existence; but political thought should recognize that some phases of life, and some lives, generate more overwhelming dependency than others (Nussbaum, 2000).

Parents or caregivers are the central and most important link in the care, education, and supervision of persons with disabilities (Kandel & Merrick, 2007). Because not all humans can develop their capabilities without help, therefore people with extraordinary challenges due to physical and or intellectual impairments are good examples, therefore parents or guardians have to play a key role in seeing that their dependants' needs are met, and their capabilities realized to

the highest possible level (Nussbaum, 2006). Such caregiving takes time and energy, and a just society should consider the burden it places on these caregivers and appropriately support them. Moreover, a good society must arrange to provide care for those in a situation of extreme dependency such as persons with disabilities, without letting parents of children with a disability be strained with the burden and consequently depriving them of other important capabilities such as bodily integrity capability (Nussbaum, 2000). On the other hand, having an effective community nursing team is of high importance for parents and carers. Community nurses are being important to service delivery as they are important by giving the necessary information and guiding parents to services that could reduce the burden of caring (Koshti-Richman, 2009).

Caring for a child with a disability needs extra support and resources to maintain the best possible growth and development of the child (Kolm, 2019). Respite care services are provided by the child and youth care centers, registered and funded according to the Children's Amendment Act. Respite care services are an alternative form of supporting parents of children with severe and intense disabilities to provide short-term relief for parents and caregivers (Integrated National Strategy on Support Services to Children with Disabilities Revised Draft, 2009). Therefore, care must be provided in such a way that the capability for the self-respect of the caregiver is not exploited and discriminated against on account of performing that role and not in such a way that the receiver is not burdened. In other words, a good society must arrange to provide care for those in a condition of extreme dependency, without taking advantage of women as they have traditionally been taken advantage of, and therefore depriving them of other fundamental capabilities. Conversely, the capability approach stresses out that people should be enabled to complete a 'normal' human lifespan; under 'health' and 'bodily integrity' (Nussbaum, 2000).

As stated by the Children's Act 2005, that in any subject regarding a child with a disability due to consideration must be given to (1) giving the child parental care, family care, or special care as and when appropriate; (2) making it possible for the child to take part in social, cultural, religious

and educational activities, acknowledging the different needs that the child might be affected by; (3) providing the child with circumstances that safeguard the dignity, promote independence and facilitate active participation in the community; and (4) offering the child and the child's caregiver with the necessary support services.

3.8 Conclusion

This chapter defined disability and developmental disability. A review of children 0-8 years with a disability was done, followed by global frameworks and policies for disability and then South African legislation was examined. The chapter further explored caring for children with disabilities. Lastly, parental care was further explored. The following chapter will be examining at the methodology of the study.

CHAPTER FOUR

METHODOLOGY

4.1 Introduction

This chapter discusses the research approach to the study. The chapter discusses the qualitative research approach, research design, the setting for the study, sampling techniques, data collection, and analysis techniques. All the techniques that were used in this study were aimed at answering

the research questions in Chapter 1. The ethics that guided the study were discussed in the last section of this chapter.

4.2 Research question

Creswell and Creswell (2017) reveal that research questions are drawn to reflect the nature of the research problem under study. Research questions set out the outline and the exact terms of inquiry required to confront the research problem, consequently a research question guides and centers your research. Flick (2018) added that research questions are important because they guide the whole research process. Therefore, a research question provides a rough idea of the issue under investigation, who was studied, and what the researcher wanted to understand about them (Connelly, 2016).

The following research question was formulated in this study:

- What is the human capability of parents and/ caregivers with children with a developmental disability?

Sarfo and Ofori, (2017) maintained that sub-questions address the main points and uncertainties to be resolved. The subsequent was the sub-questions of the study:

1. What are the bodily health and bodily integrity capabilities of parents and/ caregivers of children with developmental disabilities?
2. How is the government assisting parents or caregivers of children with disabilities in enhancing their capabilities?
3. Which programmes are available to promote the freedoms or opportunities for parents and/ caregivers of children with developmental disabilities?

4.3 Aim of the study

A research aim expresses the intention or aspiration of the research study; it summarises in a single sentence what you hope to achieve at the end of a research project. Connelly (2016) further outline specific methods and procedures the researcher employs to find the desired answers. This study aimed at exploring the human capabilities of parents of children with developmental disabilities.

4.4 Research objectives

The objectives of the study were to:

1. Explore the bodily health and bodily integrity capability of parents and/ caregivers with children with developmental disabilities;
2. Explore how government assists parents and/ caregivers of children with developmental disabilities in enhancing the human capabilities of parents;
3. Explore the programmes available to promote the freedoms and/or opportunities for parents of children with developmental disabilities.

4.5 Research Methodology

A qualitative research approach was employed to explore the human capabilities of parents and/ caregivers of children with developmental disabilities. This approach allowed the researcher to gain deep insight and understanding about the human capabilities, freedoms of parents of children with developmental disabilities in line with a study by Safe et al., (2012). Qualitative research was suitable for this study since, Braun and Clarke, (2013), alluded that it allows us to make sense of forms of meaning, nevertheless portrays the problem, mess, and contradiction that exemplifies the reality. This study limited its scope to the qualitative research method in line with the arguments by (Creswell, 2013) and (Creswell, 2009), which enabled the researcher to study social and cultural phenomena in their natural setting. In addition to this, the research employed the qualitative method because of its flexibility, meaning that it allows the researcher to adapt and freedom when

interacting with the study participants (Denscombe, 2014). For instance, qualitative research asks open-ended questions that allow the participant to respond free in their own words. This enabled the study to get full detailed responses from parents of children with disabilities rather than getting yes or no answers.

The qualitative research approach was also because it allowed the researcher to employ, “different knowledge claims, inquiry strategies, and data collection methods and analysis” (Creswell, 2009). In line with this approach, Myers (2009); Creswell (2009), points out that the sources for qualitative data include interviews and open-ended questionnaires; texts and documents; observation; and the researcher’s active reaction and impressions of experiences in the natural setting. In addition to this, this study was also guided by Denzin and Lincoln, (2000); Maree, (2007), who highlighted that in qualitative research, inductive data analysis is mostly employed, which provides a better understanding of the interaction of mutually shaping influences, and to explicate the interacting realities and experiences of researcher and participant.

An explorative research approach for the study was employed to explore new points of view or ideas, about the human capabilities of parents or caregivers with children with developmental disabilities, which was unknown, or not much known about it, to create intentions (Burns & Grove, 2005). It has been indicated that ‘this type of research design allows the researcher to develop interpretations from the views of participants, without having previous anticipations and obtain a personal understanding of the researched problem’ (Krysik & Finn, 2010, p. 309). For the current study, the focus is on the human capabilities of parents or caregivers with children with developmental disabilities and explores the bodily health and bodily integrity capability of parents with children with disabilities as well as their combined capabilities.

4.6 Research Design

This section discusses the research design adopted in this study providing a blueprint for the study. It also provides the structure of this research, showing the major parts of this study on aspects such as the samples or groups used, measures, treatments or programs, and methods of assignment work together to try to address the main research questions. It is stated by Odoh and Chinedum (2014) that the purpose of a research design is that it allows the researcher to attain new perceptions into some unusual incidences or actions, or to increase knowledge with them, to identify more exact research problems or to put together a research question. An additional purpose of a research design is to allow the researcher to define clearly and truthfully the qualities of individuals, situations, or groups, and to uncover the prevalence with which some events happen or with which view is linked with others.

An exploratory-descriptive research approach will be employed to explore new points of view or ideas, about the specified issue, which is unknown, or not much known about it, to create intentions (Burns & Grove, 2005). It has been indicated that 'this type of research design allows the researcher to develop interpretations from the views of participants, without having previous anticipations and obtain a personal understanding of the researched problem' (Krysik & Finn, 2010, p. 309). As mentioned by Burns and Grove (2005) descriptive research design is a method that gives details of characteristics of the study population, after data has been collected from a given sample. Using an exploratory research design reveals salient features of a topic, as well as its significance to the research. In this study, the focus was on the human capabilities of parents with children with disabilities and has explored their bodily health and bodily integrity capability of parents of children with disabilities as well as freedom and opportunities.

4.6.1 Research setting

The setting in which the interview takes place is very significant. If the participant is too busy, the researcher can change the location and time (Odoh & Chinedum, 2014). Approval to perform the study was obtained from the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of the Western Cape. The research was conducted in two different townships namely Kraaifontein and Fisantekraal, which are situated within the Western Cape.

Kraaifontein is a township that consists of 154,615 total populations, 10, and 5% of this population have higher education qualifications. Kraaifontein has a total of 40,169 households and 33, 2% of these households are female-headed households. Kraaifontein population comprises 50, 2% of females and 49, 8% of males. Its inhabitants are largely black Africans (43, 3%). The area also consists of a range of races including colored (40, 2%), white (14, 4%), other races (1, 7%), and Indian/Asia (0, 4%).

Understanding the demographic characteristics of children with disabilities is also significant. WHO (2012) pointed out that, due to numerous shortcomings as a result of an impairment, age, gender, or social status, a number of children with disabilities might be more subjected to discrimination and social rejection than other children. Additional main influences may take into consideration the environmental location (residing in rural and urban areas), belonging to a smaller language group, or living in conflict zones or areas of a natural disaster. For instance, girls with disabilities can be mostly at risk of being discriminated against also children from previously disadvantaged families and those from minimal traditional groups.

The second research area for the study was in Fisantekraal township with a total population of 12 369 within this population 50, 3% of the population are males and 49, 7% are females, with a total of 3 712 households and 35, % of the households are headed by a woman. A percentage of 1.1% of the population of Fisantekraal has achieved higher education. The area consists of 52% of piped

water inside a dwelling, 68, 5% of the households in the area have electricity. The area also resides of a variety of races including black (51, 5), colored (46, 9%), Indian/Asia (0, 3%), and other races (0.8%)

4.6.2 Participants

In this study, the population consists of parents or caregivers of children with developmental disabilities in the Kraaifontein and Fisantekraal areas, in Cape Town. The population refers to the individuals who hold or exhibit the feature that the researcher has spotted as the criteria, which sets the restrictions for the study (Strydom, 2011). The interest is directed to parents instead of children. The researcher had an interest in population from both Kraaifonein and Fisantekraal because both areas are low resourced areas with limited resources to assist parents of children with disabilities which in turn has an impact on their parents human capability.

4.6.3 Sample

Van den Berg and Struwig, (2017) highlights that “the study’s research objectives and the characteristics of the study population (such as size and diversity) determine which and how many people to select”. The sample was drawn from a population that met the criteria of the study: they are caregivers or parents of children with developmental disabilities; they reside in Kraaifontein and Fisantekraal locations, in Cape Town. For that reason, the study employed a non-probability purposive sampling of 12 parents or caregivers of children who have been diagnosed with a developmental disability who had been selected to participate in the study. The the study did not include parents who have children with no developmental disabilities, parents who do not reside in these two above mentioned areas and parents who have children older than the age 8 years.

4.6.3.1 Sampling Strategy- Snowball sampling

The current study made use of snowball sampling, a type of purposive sampling which is also referred to as chain referral sampling. In this technique, the participants or informants that had

contact with the researcher used their social links to direct the researcher to other people that are parents or caregivers of children with disabilities who further participated in this study. Snowball sampling uses a few participants to assist in referring the researcher other potential participants to participate in the study, in that way expanding sample size and it is a non-random sampling method. This approach is most applicable in small populations that are difficult to access due to their closed nature, for instance, secret societies and inaccessible professions (Dragan & Isaic-Maniu, 2013). The feature of this type of sampling is that it is not used to estimate the individualities of the general population but to estimate the attributes of a group of “unknown” individuals (uncommon, not easy to find). The term “very rare” population or “hard to find” population, is applied to describe in general to populations on which there is not legitimate information. “Hard to find” does not certainly have the meaning of unlawful, but unseen, not known, or unaware. Therefore, due to their scarcity, this kind of population is not easy to find, study, and recruit for the imposed research, mainly because of the ascribed social stigmatization, the legal position, and the unavailability of evident outcomes of the action of their members. (Ghaljaie, Naderifar, & Goli, 2017). For instance, the current study participants (which were parents of children with developmental disabilities) were not easy to find, therefore the researcher employed snowball sampling to gain more participants to the study through others who took part in the study.

4.7 Data collection tools

After the researcher has made the most suitable decision about the research sites, population, and data collection methods, this step was followed by a decision on the appropriate tools for the study. Therefore, the tools for the study included semi-structured interviews and the field notes that were taken during each interview. Individual interviews are one of the most reliable, commonly employed, and very traditional qualitative data collection techniques largely because of their approach. An individual or a one-on-one interview is a straightforward conversation between two

people with a certain structure and intention. The interview questionnaire is created in a way to prompts the participant's understanding or viewpoint connected to a subject or topic at hand (Creswell, 2013). Semi-structured interviews have attracted interest and are widely used. This interest is linked to the expectation that the interviewed subjects' viewpoints are more likely to be expressed in an openly designed interview situation than in a standardized interview or a questionnaire (Flick, 2018). The interview procedure allows the researcher to take notes throughout the interview about the replies of the participant. It also helps a researcher bring together ideas and views on things such as headings and sub-headings, evidence about starting the interview, concluding thoughts, information on ending the Interview, and thanking the participant (Creswell, 2009). Field notes were taken during and after the interview, which assisted the researcher when compiling most of the headings of the study. For this study, the interview schedule was developed based on the objectives of the current study. Some questions asked included questions like: Does the disability of your child affect your health? Why and how?

4.8 Data Collection Procedure

Data collection is a sequence of interconnected activities intended for gathering good information to answer developing research questions (Sarfo & Ofori, 2017). Snowball sampling technique was used in this study. Bryman (2015) opines that snowball sampling is used where possible participants are hard to find. It is therefore called snowball sampling because (in theory) once you have the ball rolling, it picks up more “snow” along the way and turns out to be bigger and bigger. The permission to conduct the study was requested from two resource constraint locations within the Western Cape. In addition to the participants, other potential samples for the study will be not only biological parents of these children but also legal guardians and carers of these children to ensure that enough data is gathered. To ensure agreement with ethical guidelines, informed consent **Appendix ...)** for the study the researcher presented to each participant with information about the intention of the study, who the research group is, how the data will be utilized, and what

involvement he or she will have need of them. That means information about the study (Appendix) was given to the participants, the aim and objectives of the study was clearly explained so that they can have an understanding of the research before participating. Semi-structured interviews are the most manner in which qualitative interviews are conducted (Braun & Clarke, 2013). According to Braun and Clarke (2013), this interview method lets the interviewer or interviewee stray in order to pursue an idea or response in more detail Therefore, semi-structured interviews (Appendix...) were conducted for the current study Therefore, data was collected through semi-structured interviews because the method allowed rich and detailed information. Brinkmann (2014) argues that an interview is a social relationship designed to exchange information between the participants and the researcher. Conversely, in the case of this study, the participants were asked open-ended questions.

The researcher conducted data collection through individual interviews, using an interview guide as well as taking of field notes. Field notes refer to minutes the researcher makes while observing behaviour and activities at the research site (Creswell, 2009). All the interviews were audio recorded with the permission of the participants using their preferred language. Most of the participants requested to be interviewed in Xhosa and only one participant preferred to be interviewed in English. Each interview took about 30- 40 minutes long and was done at the comfort of their homes.

4.8.1 Interviews

The current study has made use of one-on-one semi-structured interviews to collect data from participants. Braun and Clarke, (2013) highlighted that this, technique is important because it guides the participants and provides them with opportunities to openly discuss issues that are important to answer the main question of the study. Whilst designing the interview schedule the researcher noted that it is important to ask questions that yield as much information as possible

that help in attaining the research questions and objectives. Also, the researcher followed guidelines that in qualitative research interview questions must be open-ended being more than a yes/no answer, understandable, sensitive, and neutral.

4.8.2 Field notes

Field notes were also taken in this study to help broaden the understanding of the research questions and objectives. This was informed by Brink, (2012) who highlighted that the detailed field notes and comments taken by the researcher, contain everything that was said and done throughout the interviews. The researcher noted down her field notes directly after each interview session.

4.9 Data Analysis

This section discusses thematic analysis as the main method of data analysis that was employed in this study.

4.9.1. Thematic Analysis

The study made use of thematic data analysis, as highlighted by Nowell et al., (2017) that in qualitative research method thematic analysis can be mostly employed through a range of epistemologies and research questions. Thematic data analysis was chosen because it allowed the researcher to, it as a method to identify, analyse, categorize, describe and report themes identified in the data set as alluded by Braun and Clarke, (2006). The six phases of the thematic analytic process were followed in this study:

- **Familiarising with the data:** this process began during data collection. This study made use of textual data that includes field notes from interviews, participant observation, and reflexive journal which was done after each interview. In addition, to this the researcher also followed the suggestions by Lincoln and Guba, (1985) of triangulating diverse data

collection types increases the probability that the research findings and explanations will be found trustworthy). Additionally, to ensure clarity and gathering more data to produce valuable and reliable data, the researcher used the notion of triangulation, employing numerous sources of data (Leedy & Ormrod, 2014). The audio recorded interviews and the notes taken in the field were the data collection tools. In addition to the notion of triangulation, parents were sources of data, along with the primary caregivers of children with disabilities.

- **Creating themes:** Nowell et al., (2017) mentioned that a theme is a conceptualized unit “that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole”. In this case, the themes that were employed by the researcher were developed using deductive reasoning after data familiarisation based on the data collected.
- **Generating codes:** “Qualitative coding is a process of reflection and a way of interacting with and thinking about data” (Nowell et al., 2017). In this process the researcher engaged deeply in the collected data, identifying, and creating the building blocks of analysis. Data coding also allowed the researcher to “simplify and focus on specific characteristics of the data” (Braun & Clarke, 2012). In this study, the process adopted was open coding to code segments. In this process, codes with similarities were combined to form a new code with a broad meaning.
- **Reviewing potential themes:** in this phase, the researcher fine-tuned the themes for the study in line with suggestions by Clark & Creswell, (2014). In this study, the researcher revealed and focussed on ensuring that the themes of the study from the collected data answer the broad research aim and objectives.
- **Defining and naming themes:** refers to the process of capturing the essence of the individual theme concerning the aim of the study as highlighted by Nowell et al., (2017). In

line with this perspective, the researcher created an overall description of all the data ensuring that each theme is in line with the overall storyline of this thesis.

- **Producing a report;** “entails writing the report offers the final opportunity to make changes that strengthen the analysis and effectively communicate the analyst’s story of the data” (Nowell et al., (2017). The researcher has provided adequate evidence of each theme using clear examples where appropriate from the information used.

4.10 Trustworthiness

Connelly, (2016) suggests that trustworthiness concerning a research study refers “to the level of confidence in data, interpretation, and methods employed to certify the quality of a study”. In this study, various strategies were employed to ensure trustworthiness and as well as validity. The following are the four aspects that ensured the validity of the study:

4.10.1.) Credibility involves establishing the validity or truthfulness of the research findings. The researcher applied the method mentioned. *Truth value* is lived and perceived by participants frequently attained from the discovery of human experiences as they are (Korstjens & Moser, 2018). Thus, this study explored the true picture of human capabilities, freedoms, and opportunities of parents of children with disabilities in the natural setting.

4.10.2.) Conformability refers to whether the findings of the study can be validated by other people, and requires that the researcher maintains a neutral position, while respecting the participant’s opinions; not labelling them or influencing their views, thereby, ensuring that the findings could be confirmed (De Vos, De Hauw, & Van der Heijden, 2011). *Neutrality* implies that a research inquiry is free of bias “When a researcher or the research is said to be neutral, the inquiry is also implied to be trustworthy and legitimate” (Krefting, 1991). The researcher, in this case, respects the participants’ background, position, and perspective. After each interview session the researcher applied this concept by allowing the participants to express their own views and

comments and respecting whatever opinions or suggestions that each participants had and jotted them to the field notes.

4.10.3.) Transferability has to do with the practicability of the study: the researcher reveals that the study's findings are relevant to other perspectives (Korstjens & Moser, 2018). The researcher has ensured that adequate detail of the human capabilities of the fieldwork was provided for one to be able to decide whether the established findings apply to the other settings. In addition to the current study, the same research question guide, different set of participants were interviewed by the researcher.

4.10.4.) Dependability refers to the extent that the study could be replicated by other researchers (Krefting, 1991). For instance, if one wanted to replicate your study, they should use the same data from your research and at the same time attain similar findings. In this case, the researcher has at least strived to enable a future investigator to repeat the study. This was done by the researcher by identifying the gaps in the study to allow further researchers to fill the identified gaps in the last chapter of the study.

4.11 Ethics consideration

Ethics should be considered when researching as this helps to ensure that researchers consider the needs and concerns of their participants, and a basis for trust is established between the researcher and the participants of the study. Nussbaum (2006) emphasises the need to protect the participants from any physical or psychological harm, as well as the importance of treating them with respect and dignity. For the current study for instance, there were participants who were emotionally affected by the questions asked during the interview and were referred for counselling to the local day hospital for free counselling and further assistance offered by the local government day hospital in the area. In addition, personal information and contacts of the key informants for the

study were also kept confidential. Yin (2015) and Clark, (2012) emphasizes the prioritization of research participants the researcher was guided by the following ethical standards:

4.11.1 Permission to conduct the study

Ethical approval for the research processes was requested from the University of Western Cape's Faculty of Humanities Ethics Committee. The research was communicated with all potential participants in their language of preference, and they were offered an opportunity to ask questions before choosing to agree to take part in the research. Informed consent forms were signed before the beginning of the research. Thereafter, participants were guaranteed anonymity and confidentiality. In the circumstances of key informants, permission was requested for the use of their title, and if appropriate, their names in the report.

4.11.2 Anonymity and Confidentiality

In this study, anonymity and confidentiality were taken into consideration. Ritchie et al., (2013) argue that anonymity means protecting the identity of the participants Sarantakos (2012) adds that confidentiality entails not disclosing the contribution of the participants to everyone. In the proposed study participant confidentiality will be always sustained by securely storing data documents within locked locations. Participants interviews (audio recorder) and important documents such as interview notes will be kept on lockable storage, and all the other confidential soft copy documents related to the study will be safely stored in a password protected computer. All the above-mentioned data will be kept for the period of 5 years, and when disposing the hard copy information will be shredded and soft copies deleted.

4.11.3 Pilot study

Bryman (2015) defined the pilot study as a way of testing and confirming whether the instrument will function perfectly, this is done by first trying out with a small group of participants from the proposed target population aslo called a preliminary assessment of the interview schedule. To test

the study, a pilot study was done to clarify the application of the interview schedule questions, to be used in the main study. As a pre-test for the current study, four parents were interviewed, of the identified population and were not included in the main study. In the pilot study, the four parents were interviewed through a semi-structured interviews separately at their homes, all at different times. The significance of pilot study was that it helped the researcher to identify vague or unclear points in the interview schedule.

4.12 Conclusion

This chapter discussed the research methods used in this study. It contained an understanding of the overall process of collecting qualitative data and making sure that all ethical procedures were trailed. The chapter offered an insight into the population research design, data collection and analysis, and the research approach utilized in the study. This chapter also gave a detailed explanation of the research setting, population, and sample employed in the study. And lastly, in this chapter things like the informed consent, ethics statement, risk factors, informed consent plus confidentiality, and antinomy were further explained. The following chapter presents the results of the study.

CHAPTER FIVE

PRESENTATION OF FINDINGS AND DISCUSSION

5.1. Introduction

This section of the thesis focuses on presenting and discussing the study findings on the human capabilities of parents of children with developmental disabilities in the Kraaifontein and Fisantekraal area, Cape Town. The study was underpinned by a qualitative research approach with the use of interviews to collect data. The collected data was analysed through thematic analysis and the identified themes are presented and discussed in this chapter.

5.2. Biographical profiles of participants

5.2.1 Demographic characteristics of participants

Analysing the biographical profile of the study participants was crucial in understanding the characteristics of the participants. The participants of the study were parents or caregivers of children with developmental disabilities in Kraaifontein and Fisantekraal areas in Cape Town. The biographical information that was analysed is the age, gender, marital status, and educational level of the participants. The biographical profile of the children was also analysed to determine the age, gender, and disability type of children.

5.2.1.1. Age

Table 4.1 below shows the age characteristics of the study participants. The age of the participants was analysed to obtain a clear picture of the age groups of parents with children with developmental disabilities.

Age	Number of participants
20 - 29 years	2
30 – 39 years	3
40 – 49 years	3
50 – 59 years	3
60 years and above	0
Total	11

Table 4.1: Age of the study participants

The analysis of the age of the participants shows that there was an equal representation of parents within each age group as shown in table 4.1 above. In the study, there were 11 participants aged between 20-59 and no child was cared for by a caregiver who was 60 years old or older.

5.2.1.2. Gender

The gender of the study participants was analysed to get an understanding of the proportion of male and female participants. Generally, in South Africa, there are more females compared to males (Stats SA, 2011). Table 4.2 below presents the gender of the study participants.

Gender	Number of participants
Males	1
Females	10
Total	11

Table 4.2: Gender of the study participants

Table 4.2 shows that there are more females than males who participated in the study. This could be because South African women generally spent more time with children at home as compared to men. Hence, women are more present in the lives of children with disabilities. Some of the participants stated that the fathers of the children left them after the birth of the children arguing that they cannot live with a child with disabilities. This is substantiated by Nyakanyanga (2017) who argues that children with disabilities are often rejected by their fathers and paternal relatives. This, therefore, shows why the study had more female participants as compared to male participants.

5.2.1.3. Marital status

The marital status of the participants was analysed to determine the number of participants who are married, single, or widowed. The results of the analysis are presented in Table 4.3 below.

Marital status	Number of participants
Single	8
Married	1
Widow	1
Total	10

Table 4.3: Marital status of the study participants

The analysis of the marital status of the participants showed that most of the study participants are single parents raising their children alone. Only one participant is widowed, and another participant is married. This means that most of the responses in this study emanates from the viewpoint of single parents. Studies have shown that single mothers are more likely to parent children with disabilities (Boyce, 1994; Levine, 2009). Thus, this study had more single caregivers.

5.2.1.4. Education

Educational level	Number of participants
Standard 1 – 7	3
Grade 8 – 10	5
Grade 11 – 12	3
Total	11

Table 4.4: Educational level of the study participants

The above Table shows the educational qualifications of the study participants. According to the analysis of the participants' educational status, the study found that participants who had higher educational levels had increased capabilities to cater to the needs of their children (good food, shelter, medication, etc.).

5.2.1.5 Employment status

Table 4.5 below shows the results of the analysis of the employment characteristics of the study participants.

Employment status	Number of participants
Employed	1
Unemployed	10
Total	11

Table 4.5: Employment status of the study participants

The employment status of the participants was analysed to determine the participants' capabilities to cater to the needs of their children with developmental disabilities. The majority of the participants reported that they were unemployed. Only one participant was employed. The study

found that the employment status of the parent/caregiver has a bearing on their bodily health and bodily integrity capabilities. The participant who reported being employed stated that the child has access to good food, shelter, and health, unlike the other participants who are unemployed.

Most of the unemployed participants reported that they were working before, but they had to stop working after the birth of their children since they realized that the children need a lot of their attention. However, due to their unemployment, they are failing to afford good health, shelter, good food, and being able to move comfortably with their children to the hospital for medical check-ups as they cannot afford comfortable transport costs. This means that the employment status of the caregivers contributes to their capability to bodily health and bodily integrity. The study by (Ejiri and Matsuzawa, (2019) indicated that caregivers of children with developmental disabilities' better health, better education, and availability of social support were associated with their employment. Therefore, the employment status of parents or caregivers may influence caregiving of the disabled child, the employment of a parent or caregiver results in reduced time available for being productive at home, for caregiving. Also, parental unemployment may lead to a lack the financial means lead to poverty.

5.2.2. Biographical information of children

The biographical information of the children was also analysed and the results of the analysis are presented below. The biographical information of the children was analysed to determine the age, gender, and type of disability.

5.2.2.1. Age and gender

The age and gender of the children were analysed, and the results of the analysis are shown in Table 4.6 below.

Gender			Age			
Boys	Girls	Total	0 – 3 years	4 – 7 years	8 - 10 years	Total
8	3	11	3	5	3	11

Table 4.6: Age and gender of the children

This study aimed at exploring the human capabilities of parents or caregivers of children with developmental disabilities who are aged between 0 and 8 years. Thus, all 11 children in this study were aged 8 years and younger. The majority of the children were boys (7 children), and girls were only 3.

5.2.2.2. Disability classification

The study analysed the children's disabilities to determine the classification of disabilities. The classification of the disabilities is presented in Table 4.7 below.

Disability classification	Number of children
Cerebral palsy	3
Autism	4
Down syndrome	1
Fetal Alcohol Syndrome	1
Intellectual disability	1
Unclassified	1
Total	11

Table 4.7: The children's disability classifications

The majority of the children have cerebral palsy and autism. Cerebral palsy relates to motor impairments that are due to a non-progressive interference, lesion, or abnormality of the developing brain (Blair & Cans, 2018). The caregivers of children with cerebral palsy in this study reported that the children have difficulties in walking, hearing, and bodily movements. Ousley and Cermak (2013) define autism as a neurodevelopmental disorder associated with the presence of social-communication deficits and restricted as well as repetitive behavior. All the classified disability types in Table 4.7 have been diagnosed by medical practitioners and the children are receiving medical treatment. However, one caregiver reported that the child has not been to the doctors for examination and therefore the disability type is not known. This child is being cared for by the grandmother, the child's parents are alive, but they are not involved in the child's life.

5.3. Presentation and Discussion of findings

The results of the study are presented as they appeared from the analysed data of word for word recorded, semi-structured interviews, and field notes. The labelling of the themes and sub-themes that came out of the collected data codes are based on the study outcomes. The exploration of the human capabilities of parents with children with disabilities, themes used in the study came about to better understand the human capabilities and sub-themes across all three different capabilities (bodily health, bodily integrity, and combined capability) chosen for the study. Therefore, all three themes had different sub-themes that contained all the necessary information entailed in each capability. The first theme had five sub-themes, the second theme had two sub-themes and then the third theme had eight sub-themes. In all three themes the descriptions of the results are presented, reviewed, and substantiated by participants' word to word citations from the recorded data, to establish the participant's legitimacy. Furthermore, where obtainable, related literature reference is made to support or disprove the themes that come from the study.

Table 5.3: Themes and sub-themes

THEME	SUB-THEMES
1: The bodily health of caregivers of children with disabilities (5.3.1.)	Sub-theme: 5.3.1.1. Good health
	Sub-theme: 5.3.1.2. Access to good food
	Sub-theme: 5.3.1.3. Adequate shelter
	Sub-theme: 5.3.1.4. Exercising
	Sub-theme: 5.3.1.5. Access to medical help
2: The bodily integrity of caregivers of children with disabilities (5.3.2)	Sub-theme 5.3.2.1: Freedom of movement
	Sub-theme 5.3.2.2: Security against violence and discrimination
3: The Combined capability of parents with children with disabilities (5.3.3)	Sub-theme 5.3.3.1: Interventions to assist parents/ caregivers of children with developmental disabilities
	Sub-theme 5.3.3.2: Disability grant
	Sub-theme 5.3.3.3: Food assistance
	Sub-theme 5.3.3.4: Programmes available to promote the freedom/ opportunities of parents and or caregivers of children with disabilities
	Sub-theme 5.3.3.5: Support groups
	Sub-theme 5.3.3.6: Counselling
	Sub-theme 5.3.3.7: School program
	Sub-theme 5.3.3.8: Online program

5.3.1. Theme 1: The bodily health of caregivers of children with disabilities

The results of the study indicated that most parents knew about the importance of bodily health and had different ways to ensure that their bodily health is taken care of or maintained well. This study explored the bodily health capabilities of caregivers of children with disabilities. Bodily health refers to the complete body health of an individual's healthfully acknowledging the mental, social, physical, spiritual, and emotional factors in a person's ability to thrive and not merely survive (Wright, 2019). Nussbaum (2000) argues that bodily health relates to being able to live with good health, having access to medical help when needed, having good food, and being able to exercise to sustain health. Mörelius and Hemmingsson (2013), also indicated that parents of developmentally disabled children are at risk of reduced health-related quality of life, particularly concerning everyday tasks, sleep, energy, stressful emotions, and communal activities.

Research shows that taking care of a child with a disability could negatively influence parents' bodily health, relationships with society, autonomy and freedom, family relationships, and financial obligation. Therefore, the bodily health of parents is directly influenced by their way of behaving and lifestyles. How caregivers deal with their physical, emotional, and social well-being has an impact on their adaptation to their child's condition. Signifying those greater levels of self-perception, self-mastery, confidence, self-efficacy, and management of anxiety or strain all have a positive impact on the psychological health of the caregivers or parents (Pousada, et al, 2013). Nussbaum's health-related examples from Nussbaum's list should all be considered necessary functionings, and the related capabilities are (as for overall health) about maintaining those health-related functionings. To be sustained or prolonged, they also, among other things, need that the individual to be simply healthy, for instance, can exercise, can understand health information, and can make knowledgeable and balanced choices regarding health. Therefore, this means that employing the capability approach within a health promotion project may enhance the target group's compliance by concentrating on how to positively change the opportunities for health that

they regard as important and necessary, rather than simply “compelling” them to act healthily to accomplish a positive change of health result. In brief, the capability suggested that stay healthy or sustain health, and Nussbaum’s second capability is to have good bodily health (Tengaland, 2020). Some of the participants viewed good health as:

...eat healthier food which includes fruits and vegetables and some of them have higher protein which will make us live a healthier life (Participant 5)

eat good food not food with too many fats...eating things that will be beneficial for my health. (Participant 1)

I walk as part of my exercises, walking is a good exercise (Participant 10)

For mental health I usually talk with my neighbor, we go to the same church (Participant 2)

The responses from the participants show that they understand what bodily health is. The responses capture issues of having good food, being able to exercise, and sustaining health as discussed by Nussbaum (2000). This in terms of Nussbaum (2011) means that the capability approach may help achieve this change of healthy eating or engaging in healthy activity by pointing to the advantages in terms of capabilities for healthy actions. It looks at obtainable or unobtainable mechanisms which may have led to the particular result and respects individuals’ freedom to choose for or against a healthy behavior. This means that the parents have the necessary information of what it entails to be healthy healthy individuals and make use of the healthy ways accessible to them.

5.3.1.1. Good health

Nussbaum (2000, 2006, 2011), alternatively, has recommended a list containing ten capabilities that she finds especially vital, and possibly all-inclusive, and is more explicit about the capabilities. Her list of capabilities includes health. Therefore, Nussbaum mentions health, as part of a person’s

internal lively circumstances (Tengaland, 2020). The participants were asked to define good health as they understand it and most of the participants were able to define what good health means to them. Most of the participants perceived good health as eating the right or healthy food, drinking a lot of water, being emotionally well, and doing exercises. Others perceived good health as being physically and mentally fit, free from diseases. Despite knowing what good health means and what one needs to do to have good health, most of the participants stated that they do not have good health as they have some physical and emotional challenges. This means that they lack some of the capabilities that are fundamental to every human being meaning that they are living a life that is not worth living as according to Tengaland (2020) lacking a capability is lacking a sufficient degree of at least one factor that is essential for realising the functioning in inquiry. As parents were evaluated based on their good health, most participants/parents indicated a lack in the capability of good health as they mentioned that,

I am not emotionally fine. The life that I am living is very painful because other people who have children who do not have disabilities do not live this kind of life that I am living. I feel like I am not living a proper life because most of the time I do not get enough space to be. At times I do think about working but I can't because of my son's life. I must look after him. I also have arthritis and it is difficult for me to take my child to the hospital (Participant 1)

I do not know the life of being happy. I can say living like this is very hard and painful because there are times of hardship. (Participant 9)

Physically I can say, I am okay but now emotionally I am not. I get drained because when you have a child with a disability automatically your mindset will not be the same as that of a mother whose child does not a disability. (Participant 8)

The above statements show that the caregivers of children with developmental disabilities are finding it difficult to raise their children because of the emotional stress attached to parenting a

child with disabilities. Some of the participants have physical health issues, for instance, participant 1 has arthritis which affects their ability to adequately care for their children. Thwala et al., (2015) argue that raising a child with disabilities is often challenging for most parents. Often challenging because of the requirements associated with care, not adjusting appropriately to the situation of the child, that in turn have a negative consequence on the physical and mental health of caregivers (Ahmadizadeh et al., 2015). Likewise, providing a high level of care that is required by a child with long-term functional limitations might have an emotional impact on the health of the parents. Parents supervising and dealing with the child's illness might be impacted by emotional complications such as depression. Emotional strain in a parent may cause emotional and psychiatric strain in the child and may have an impact on the family's ability to cope with the child's disability; therefore, the disability may have a bigger influence on the parent's health (Hung et al., 2010). The findings are consistent with the results of the study by (Mörelus and Hemmingsson, 2014) which indicated that both parents of a child with physical disability reported reduced health, emotional tiredness, staying up at night more and interrupted sleep, in cases of a child with sleeping challenges. Mothers also reported more headaches when the child had sleep problems. The findings of the study further revealed that both parents reported additional night-time wakefulness and sleep disturbances when the child needs attention during the night. This concurs with the findings of this research since the majority indicated that their emotional health is affected. The caregivers are worried about the future of their children if they are no more. This means that caring for a child with developmental disability has an impact of their caregiver's health and that the health of caregivers is of high importance as they are the main supporting structures to their children. The research was done in this field by Muller-Kluits and Slabbert (2018) also revealed that because of the care burden for an individual with a disability, caregivers are likely to rate their own health needs very minimal. Caregivers in this study expressed continuing exhaustion, lack of sleep, and persistent bodily complaints or pain. This is in line with some of the

experiences of the participants regarding their physical health, as well as back problems, sleeplessness, and overall strain concerning the physical responsibility of caring for a child with a disability.

5.3.1.2. Access to good food

Concerning bodily health, Nussbaum (2000) argues that access to good food is fundamental. A child lacking in the capability of obtaining suitable nutrition will be starved and her health compromised, regardless of whether his/her parents do not have the means to offer sufficient food or are intentionally not supporting the child. Structural concerns are essential to children's well-being and attending to the health and child welfare imbalances is an issue of human rights and social justice (Gupta et al., 2016). Thus, the participants in this study were asked if they are well-nourished. However, many of the participants argued that they are not well nourished as they cannot afford to buy good and healthy food. The caregivers reported that only consider the price of food commodities when buying groceries and they buy the cheapest. Since most of the participants are unemployed, they are always at the home taking care of their children with disabilities, therefore, they do not have adequate sources of income. For many, the only source of the household's income is the disability grant which is not sufficient to cater to the household's food needs to sustain them for the month. Since most participants who took part in this study indicated that they are unemployed meaning that their financial status is not satisfactory as indicated by their responses below. On the other hand, a study by Ahmadizadeh et al., (2015) also revealed an important outcome which indicated that having a full-time job has a link with the quality of life of all parents. This means that having a permanent job, the social life of parents is largely well-maintained and, possibly, it is a limiting factor of caring for a child. For example taking care of a child with cerebral palsy can have an impact on the family's financial state, as the existence of a child with cerebral palsy can cause a huge financial load on families. The

participants showed that they are knowledgeable about healthy eating, but they reported that they are not adequately nourished because food is expensive.

One participant argued that they eat food that they know is not healthy “*because it is affordable*”. The other participants stated that they are diagnosed with diabetes, high blood pressure and are also living with HIV and were told by doctors to eat vegetables and a lot of fruits. However, access to fruits is a challenge to them, for instance, participant 6 said,

I was told by the doctor to eat a lot of fruits because of my health condition, but to me fruits are expensive. The money I receive as the grant is not sufficient to cater to all the needs of my child so I cannot afford to buy fruits for myself because I do not have any other source of money besides the grant money.

According to Park, Kim, Kim, Jeoung, and Park (2020), lack of food is the biggest nutrition and health challenge and remains high on the policy agendas of most countries. There have been many efforts towards defining and improving the lack of food at the global, national, household, and individual levels, and substantial progress has been made to this end over the last few decades. Nevertheless, almost 2 billion people globally are subjected to a lack of food in 2018; therefore, a huge number of people still do not have consistent access to adequately reliable and healthy food. Thus, it is evident that the caregivers are not adequately nourished which consequently has an impact on their capability to care for their children with disabilities. This is substantiated by literature which states that the ability of parents to adequately care for their children and themselves is affected by the presence of deprivation including poverty and unemployment meaning that poverty has a negative impact on parent’s ability to take care of their children (Ward, et al., 2014). As such, due to poverty and unemployment, most of the caregivers in this study stated that they have limited access to good food. Govender et al., (2017) accentuate that lack of access to a nutritious and well-balanced diet is a major impediment to health and well-being.

In addition, the majority of the caregivers in this study indicated that they are unemployed, mainly due to the condition of their children as the children require their full attention. Therefore, the unemployment status of the participants contributes immensely towards the caregivers' lack of access to good food. Meaning that most participants are not eating what they desire or what they should be eating but are forced by circumstances to eat whatever is available to them just for survival.

Notably, some stated that they have access to good health, although they were a few. One of the participants argued that they were not eating healthily in the past, but after knowing that they should eat healthy food, she is now making sure that she eats healthy food.

...now I am making sure that I eat my meals three times a day and that I drink water every day and that I eat enough fruits and vegetables and stuff like that. (Participant 4)

The above response from participant 4 of this study is evident that she has access to good food as she stated that she ensures that she eats three meals a day, water, and enough fruits. Therefore, most of the participants could not maintain bodily health. As documented by Park et al., (2020), food-insecure households are more likely than food-secure households to include someone with a disability. Therefore, the unemployment rate for families with persons with disabilities tends to be higher, low incomes, and major extra expenditures triggered by disability. The higher prevalence of family's lack of food regularly witnessed in homes with people with disabilities implies that disability might lead to greater nutritional and health inequalities to the caregivers or family. It further indicates that existing food support assistances and disability grants are not adequately accommodating and useful in decreasing the lack of food amongst homes affected by disabilities.

5.3.1.3. Adequate shelter

As Nussbaum (2002) mentioned that all ten items mentioned in her list as essential and together adequate for the good human life, therefore, suitable shelter or housing is of the same importance

as the other ten capabilities. The results of the study indicated that participants do not afford decent and adequate shelter for both themselves and their children. This is elucidated by some participants who stated that:

...we used to stay in a shack that was water leaking and in a bad condition ... the place we are staying now does not accommodate him. (Participant 1)

It is very good, it has just been built by the government, it was built for him because of his condition, he is disabled, we have just got in, and at first it was a shack now it has been built by bricks. The people who built this house said that they will come and fix it for him as he will be growing, they said they will add rails and bars as he will be growing older, but they never came back. (Participant 2)

No, the house does not accommodate him (Participant 3)

The condition of this house does not accommodate him because our space is small. Because he is a person walking in a wheelchair, he does not have space, so he stays in one place he roams in one place. (Participant 9)

The above findings from the participants indicate that both the caregivers and their children lack access to good accommodation. This shows that the state of shelter that the participants rely on as accommodation is not adequate and suitable for them and their children. Some participants have one-room accommodation which they share with the children. Many of the caregivers in the study reported that they do not own a house and rely on renting out a room for themselves and the child. According to Gupta et al., (2016), it is evident that an individual's capabilities are substantially influenced by both past and present environmental and social conditions. This view of society is based upon a contextual idea of causality that is flexible enough to integrate both individual and social effects into social inquiry. When taking into account the lack or the shortage of a specific capability, attention is directed to the related underlying channels accountable. For instance, the

capability to have suitable housing for one's family depends on having relevant resources (RDP house, employment, etc.).

However, a few of the caregivers can maintain bodily health through having access to adequate shelter. The participants who can have access to adequate shelter stated that,

"It is very good, it has just been built by the government, it was built for him because of his condition, he is disabled, we have just got in, and at first it was a shack now it has been built by bricks." (Participant 2)

...we have everything in the house, like a bathroom, we have our room and all that
(Participant 4)

"I always make sure that my household is comfortable for my son and knowing what disability he has putting him in a difficult environment, won't be able to adapt and will be difficult for him, so I make sure that there is always uhm there's always water and electricity...." (Participant 5)

Thus, like access to good food, the capability of having access to adequate shelter is also a challenge for most of the caregivers in the study. Only a few of the participants are capable to maintain bodily health through having access to adequate shelter for both themselves and the children under their care. Some of their responses included that:

"No (shakes head) it does not accommodate him. Even this house is not under my name. I am still promised to be given my own house. I don't even know if God will help me also in this. I am a person who has been promised a place of my own, they said that there is a place that is currently being built here in Kraaifontein, and my things are already in Scottsedene. Before staying in this house, we used to stay in a shack that was water leaking in a bad condition. I'm just grateful that it has finally been built". (Participant 1)

“As you can see, this is an RDP house, when you have a child who is living with a disability, they need space more, space I think has a thing it does to your brain. A space that is cramped and small like this one affects you one way or another because, it’s me this child, and these two you see and sometimes we get visitors some of our relatives, you just feel like you are closed in.”
(Participant 8)

“Ohh it’s a one-room, it is a one-room small for me and my boy....; The toilet we go inside in the house to the toilet then now because boy uses nappies.” (Participant 6)

“The condition of this house does not accommodate him because our space is small. Because he is a person walking with a wheelchair, he does not have space, so he stays in one place he roams in one place.” (Participant 9)

The majority reported that the shelter they have is not suitable to cater to the needs of their children. The caregivers feel that they are failing to provide adequate shelter for their children. Drawing on the Capabilities Approach, it shows that the caregivers of children with developmental disabilities who took part in this study lack bodily health to some extent. This is because Nussbaum (2003) argues that people need to be capable of having adequate shelter.

5.3.1.4. Exercising

Exercising is linked to bodily health capability (Nussbaum, 2000). The participants were asked about their exercising habits. For instance, a study by Muller-Kluits and Slabbert (2018) also found out that the caregivers revealed that most of their time and effort was assigned in taking care their child and family members to often put their own health needs as the lowest priority. The majority stated that the only exercise they do is doing household chores and cannot either go for early morning jogs or to the gym. The participants know that they need to exercise to keep themselves healthy, but they do not do so. Only a few participants reported that they do exercises.

I got a stroke in July, so the doctors said that I must exercise every morning... Even during the day when I get a chance. (Participant 2)

I am always working here in the house; it is the only way I can say I exercise (Participant 3)

I jog twice a week (Participant 4)

I walk as part of my exercises, walking is a good exercise (Participant 10)

Participants are knowledgeable about the need to exercise. However, only a few of them do the exercises. One of the participants reported that he does exercise since it was an order from her doctor to do exercises because of her stroke. Nussbaum (2003) argues that exercising is vital in sustaining good health. Thus, the fact that some of the participants do exercises is an indication that they somehow have access to good health which is in line with the capability approach.

5.3.1.5. Access to medical help

Nussbaum (2011) applies the notion of capabilities to expand viewpoint about social justice and a country's basic responsibilities for its citizens. Nussbaum's main capabilities are closely linked to rights; like rights, they consist of the notion of entitlement. The participants were also asked if they have access to medical help when they need it. The majority of the participants agreed that they have access to medical help. The participants stated that they visit the nearest medical hospitals for assistance with their medical needs.

I go to the clinic whenever I need medical help (Participant 8)

I go to Day Hospital and Tygerberg Hospital they do offer counseling services there. I do go there if I am troubled emotionally or when I feel that my head is heavy when I have something that I need. Shame I do not want to lie they do help me then step by step I become better. In most cases I do want to commit suicide, I feel like it might be better if I am not

alive to see them struggling to get things I go anytime when I feel something because a lot of things tend to make me sick, and I end up in Tygerberg hospital (Participant 1)

I only go to those doctors at the Day Hospital, I have never gone to the private doctors. (Participant 2)

I go to the nearest public clinics (Participant 4)

From the above responses, it shows that the caregivers of children with developmental disabilities who took part in this study have bodily health as they can have access to medical help to maintain good health.

From the analysis of the findings, the study found that the majority of the parents/ caregivers of children with developmental disabilities had limited bodily health capabilities as they indicated that they do not have access to good food because they cannot afford it. This can be alluded to the fact that most of the participants are not working (see table 4.5) because of their children's conditions, and the only source of income available to them is the government's disability grant which is not sufficient to cater for the needs of the children. This concurs with Lindo, Kliemann, Combes, and Frank's (2016) argument that there is a financial burden linked with having access to health, education, accommodations, transportation, medications, and special food for households with people with disabilities.

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to health, education, accommodations, transportation, medications, and special food for households with people with disabilities.

5.3.2. Theme 2: The bodily integrity of caregivers of children with disabilities

This study also explored the bodily integrity capabilities of parents or caregivers of children with developmental disabilities. According to Nussbaum (2000), bodily integrity is one of the essential human capabilities. The data presented in this section of the study relates to the bodily integrity of caregivers who took part in this study. According to the Capabilities Approach, which underpinned this study, bodily integrity refers to the ability of individuals to be able to move freely from one place to another, being secure against violent assault, and having opportunities for sexual satisfaction (Nussbaum, 2003). Literature has shown that bodily integrity sums up the right of everyone to autonomy and self-determination (Nussbaum, 2003; Patosalmi, 2009).

5.3.2.1. Freedom of movement

The participants were asked if they can move freely from one place to another. This question was asked about determining the participants' bodily integrity. According to Nussbaum (2000 p. 78), bodily integrity refers to "being able to move freely from place to place". The majority of the participants argued that they are derailed from freely moving from one place to another as a result of their children's disabilities. In most instances, when moving, they require to hire a car so that they can be able to go with the child to the hospital. The participants also stated that they are usually at their homesteads all the time since the children constantly need to be checked so that they cannot harm themselves.

Yhooo it pains me a lot when I know that I'll be traveling with him because I know I will struggle, when I have to go with him, it affects me. I thank God when I come back from that trip with him and having a smooth journey with him...Our trips are always painful
(Participant 1)

It is painful, ... at times I even cry, in the taxi people are in a hurry they want to get to work, and the taxi would be stationary for a while whilst we try and get him off the taxi.... sometimes drivers shout, “get this child of yours on board we want to leave we are late”. Going to the hospital becomes a very painful day. (Participant 2)

I am that mother that wherever I go I know I must quickly come back. I don't have the liberty of staying and shopping around (Participant 8)

“I usually I ... I carry him on my back then now when we are inside the taxi you would notice maybe you see that thing of a person being like (showing by action), a person doesn't him to sit next to them maybe a person would say... (Participant 8).

Drawing from Nussbaum's (2000) capabilities approach, it can be inferred that the caregivers of children with developmental disabilities lack bodily integrity as they are unable to move freely from place to place because of the situation of their children.

5.3.2.2. Security against violence and discrimination

Nussbaum (1993) also argues that bodily integrity entails being able to be secure against assault including sexual abuse or domestic violence. In South Africa, people with disabilities and those close to them are often susceptible to multiple forms of discrimination in various social spheres (Stats SA general household survey, 2016). It is also against this background that this study sought to examine the bodily health of caregivers of children with developmental disabilities. The participants highlighted that they encounter discrimination on several occasions from community members and family at times.

Yes, I encounter discrimination so much, as a result, we have a case that is still pending in court again. People here in the community refer to him in a very painful manner saying that “that kid who is disabled. (Participant 1)

Yes, we experience discrimination, you see in the neighborhood the place that you think you will be understood, you can hear the hurtful comments of the neighbors, and they don't sit well with me.... It smashes my soul, it smashes my soul so much, you find out that it seems like you have given birth to an animal, yet I gave birth to a human being.... it's not nice in general to have a child who is dealing with a disability, people see it as a curse I would say. (Participant 8)

When arguing someone insulted me with my child's condition, I was pained because she insulted me about my child. (Participant 9)

...many people always have something to say about my child's disability, I was very young when I got pregnant with her. At first, I didn't know that I was pregnant and that's why I drank so much. People now always judge me because my child has this condition. (Participant 4)

...there is something that was said by my cousin's sister which was hurting me. She said my child is a cripple. Another girl asked me to take him down so that she can see what is funny with this child. (Participant 7)

Notably, some of the participants stated that they have never encountered abuse or any form of discrimination due to their children's condition.

No, I would be lying, I have not faced any abuse or discrimination in the community. (Participant 2)

However, there are only a few caregivers who have security from violence and discrimination. The majority of the caregivers are being insulted and told hurtful words. This, therefore, calls for the need to conduct awareness campaigns or programmes to buttress social cohesion and reducing vulnerability, abuse, or discrimination (DSD, DWCPD & UNICEF, 2012).

5.3.3. Theme 3: Combined capability

Combined capabilities consider the method of bringing together the person's abilities and political, social, and economic settings that maintain the capabilities made from opportunities or freedoms. Nonetheless, internal capabilities are established in collaboration with the economic, communal, family, and political surroundings. The role of the public and governments is to build settings that enable opportunities for people to operate and promote the improvement of internal capabilities in line with these capabilities (Gupta et al., 2016). The participants were asked about the form of support they receive from the government, or their community and the majority of the participants were able to say what kinds of support they receive from their immediate environment and how it is assisting them. The majority of the participants received a disability grant for their child and is the only source of income or support. Others mentioned that they also receive other forms of support from the community such as food parcels and free counseling. Despite the one-on-one support received from the community and governmental structures, one parent also revealed that she makes use of online supporting programmes as her way of dealing with the situation.

5.3.3.1 Interventions to assist parents/caregivers of children with developmental disabilities.

The capabilities approach views the government as having the duty to provide for the population (Nussbaum, 2000). A study by Muller-Kluits and Slabbert (2018) discovered that participants in this study appeared to experience numerous levels of the caregiver burden. The interviews done with the participants in the study made apparent that most participants were strained with physical, emotional, financial and social issues. The study further specified that the care responsibilities linked with caring for a disabled child were therefore limiting the family caregiver in finding employment opportunities, which in sequence might lead to greater financial strain, as well as influencing the caregiver's health. Thus, this section of the study presents the study findings

relating to the available interventions by the community, the government, or NGOs aimed at assisting the parents/caregivers of children with developmental disabilities within the studied area.

5.3.3.2. Disability grant

It has been indicated by Muller-Kluits and Slabbert (2018) that having a child with a disability has an impact in the families financial affairs. This is mainly because of the challenges they endure in finding suitable and inexpensive child care, the out-of-pocket expenses of medical care and other services may possibly be extensive, and they might have to depend on public support and care. As previously specified that caring for a child with a disability is frequently a life-long obligation, obviously and therefore requires more financial assistance (Muller-Kluits & Slabbert, 2018). The study participants stated that they receive a disability grant from the government through the Department of Social Development. The disability grant is meant to assist the caregivers of children with disabilities to be able to cater to the children's needs. The participants stated that,

The only support I get from the Government is his disability grant. I use his disability grant to buy him food, clothes, and other things he needs. However, the disability grant is not enough. (Participant 1)

Another participant stated that,

It is really bad because I am not working. I only get the child's disability grant, but it is not enough since I need money for rent, food, and medical needs. (Participant 6)

This shows that the government is trying to support caregivers of children with disabilities so that they can afford to provide a decent life for the child. Literature has shown that support systems play a significant role in ensuring that families cope with caring for children with disabilities (Kandel & Merrick, 2007). Thus, the disability grant in this instance is a formal support system initiated by the government to provide a safety net for caregivers of children with disabilities.

Nonetheless, in as much as the participants are receiving a grant from the government, they feel that the grant money is not adequate. Participant 6 argued that “*there must be maybe an increase in that grant money that a person gets from the government*”.

On the other hand, some participants argued that they are not even getting the disability grant which makes life difficult for them and the child under their care. This is elucidated by participant 4 who stated that,

I am not receiving any form of support from the government. The only support I get is from my family.

Lack of monetary support generates a secondary issue of financial challenges, such as the inability to gain access to specific services. For instance, parents may not be able to pay for private or special schooling, would need to make use of public medical services and public transport, and would most probably be unable to keep money aside in a trust fund for the child (Muller-Kluis and Slabbert, 2018). Since almost all the parents who took part in the study were not working, the assistance from Government came in handy to them.

5.3.3.3. Food assistance

In a study by (Muller-Kluis and Slabbert, 2018) it was identified that parents of persons with disabilities identified several barriers to accessing social resources (such as governmental resources aimed at assisting parents caring for children with disabilities on a full time basis). One of the intervention strategies to assist parents/ caregivers of children with disabilities is food assistance which is often given by the government through the Department of Social Development. Food assistance is given to ensure that the caregivers can provide food for their children. One of the participants said,

Sometimes they call us into the hall and Social Development will distribute food parcels although the food items are small and few. Sometimes you find it will be only 2 kgs mealie meal and 750g of cooking oil but then it is not the same it closes a gap. (Participant 8)

Thus, it is evident that caregivers get food assistance from the government. However, the participants argue that the food assistance they get is not sufficient as they are only given a few food parcels which do not consist of all the basic food commodities.

5.3.3.4. Programmes available to promote the freedoms and/or opportunities for parents and/ caregivers of children with developmental disabilities

This section presents the programmes that are available to promote the opportunities for caregivers of children with developmental disabilities. The data presented in this section were derived from interviews conducted with parents/ caregivers of children with developmental disabilities who participated in this study. The majority of the participants in the study argued that there are no available programmes within their community that promote freedoms/ opportunities for parents/ caregivers of children with developmental disabilities.

The participants are therefore subjected to stress and anxiety as some of them are not even fully knowledgeable regarding the disabilities their children have. Thus, it is imperative for both the government and NGOs to develop and strengthen programs to support parents/ caregivers within the Kraaifontein and Fisantekraal locations in the Western Cape provinces. This will enable the caregivers to cope with their situations and consequently increase their capabilities. The majority of the participants stated that they are unemployed (see table 4.5). As such, there is a need for sustainable livelihood projects within the areas to enable the participants to have a source of income to sustain themselves and the children under them so that they can afford good food, good health, and shelter.

Only a few participants indicated that there are some programmes meant for caregivers of children with disabilities within their communities. The few programmes that were identified are discussed below.

5.3.3.5. Support groups

A study by Oh and Lee (2009) that examined caregiver burden and social supports perceived by mothers raising children with developmental disabilities in South Korea indicated that participants conveyed a high level of general burden, especially in monetary domains. The findings of the study specified that social support could lessen this burden experienced by parents of children with developmental disabilities. Support groups were one of the programmes that the participants of this study mentioned that are accessible to them. The support groups are reported to be mainly found in clinics. This is elucidated by one participant who stated that;

There is a support group at the clinic where I usually go ... it is of great help for me because the people there do not judge each other, and all the mothers face the same challenges, and we are in the same situation. If you have a problem, you can go to the Clinic and speak to a facilitator, and they will help you and guide you (Participant 4)

The above statement shows that the caregivers of children with developmental disabilities cope better with the help of support groups where they will share their experiences with other caregivers of children with a similar disability. However, the support groups are not found in all the communities or some caregivers of children with developmental disabilities are not aware of the availability of the support groups. Most of the study participants argued that there are no support groups for caregivers with children with disabilities in their areas.

Also, one of the participants expressed her need for these support groups to be established within their community. To elucidate this view, participant 3 argued that *“I would love to see us parents with children with disabilities like to have a group or a place where we meet as parents and speak*

about our children". This shows that at times the parents are emotionally drained, and they need emotional support from others who are experiencing life as them so that they find comfort.

Literature shows that caring for children with disabilities is stressful (Shandra, Hogan & Spearin, 2008). Thus, there is a need for the establishment of well-functioning support groups within the communities to assist the caregivers of children with developmental disabilities. As discussed in Chapter 3 of this study, the support groups or programs afford caregivers of children with disabilities to get together to share common experiences and concerns (National Academies of Sciences, Engineering & Medicine, 2016). Therefore, through these support groups, the caregivers would share their experiences with others who have children with similar disabilities and support each other.

5.3.3.6. Counselling

A South African study by Ward et al., (2015) indicated that parenting is certainly key to every child's development, similarly important is the communal support systems that are available to parents or families of these children. Specifically, families of parents with children with disabilities may benefit mostly from more focused parenting support, such as parenting programmes. Thus, all families need some support, such as finances and access to health care, education and emotional support in order to fulfil the basic tasks of providing for children. The WHO (2012) revealed that when it comes to parents of children with similar disabilities, things like group discussions, face to face listening, support groups and other imaginable interventions can grant them with opportunities to share experiences and promote fellow assistance and encouragement. Another program accessible to caregivers of children with disabilities is counseling. Some of the study participants stated that they go for counseling whenever they feel overwhelmed by their situation. This is elucidated by one participant who argued that,

I do go for counseling when I have a lot going on in my mind... finding out that I had a lot of diseases and the condition of my child made me fear ... but because of consistent counseling, here I am today. I go to Day Hospital and Tygerberg Hospital for counseling services when I am troubled emotionally. (Participant 1)

The participants feel that counseling helps them to lessen the burden. Sammon and Burchell (2018) argue that counseling for families with children with disabilities is essential in restoring the wellbeing of the whole family. Similarly, this study found that counseling is helpful for the caregivers of children with developmental disabilities.

5.3.3.7. School program

Finding by the WHO (2012) revealed that, as children become older, access to early childhood education and transition to the first grades of primary school are also essential to establishing the foundation for continual learning and development. When comparing children with disabilities and those without disabilities, it has been found out that those with disabilities are rating low of remaining in school and are less probable to start school. It is estimated that one third of all primary aged children who are not in school are children with a disability. Those in school are all too often excluded within the school setting, are not placed with peers in their own age group and receive poor-quality learning opportunities (WHO, 2012). Another program that was identified by the participants in the school program is operational in one of the studied areas. This program is run to assist the teachers and parents in taking care of children with disabilities. One participant stated that,

In our area, there is a crèche type of school place where there are facilities for children with disabilities. The teachers and caregivers are taught how to look after such children (Participant 5)

Thus, the program is beneficial to the caregivers as it exposes them to the knowledge and skills of caring for their children who are living with disabilities. There is, therefore, a need to strengthen this initiative within the community and extend it to other areas.

5.3.3.8. Online program

In as much as the caregivers expressed their need for programs that engage them in ensuring that opportunities enable them to take care of their children are available to them. However in the study by Muller-Kluits and Slabbert (2018) it was indicated that the majority of the participants who took part in the study the pointed ou that the lack of finances was a major barrier in caretaking, particularly for those who were unemployed. When parents lack finances this means that they would have no means to access the available online services of assistance or required online information. One participant expressed that such programs are scarce. As such the participant argued that there are internet platforms that make available opportunities for caregivers. The participant stated that.

There are a lot of programs on the internet where parents talk about their children's disabilities, and it helps them to maintain their happy life with the child knowing that it is difficult but there is always a way to assist the child. People on these platforms are always willing to give advice (Participant 5)

This is a good initiative. However, this is not affordable since it requires internet access which might not be possible for most of the caregivers of children with disabilities due to the high costs of data.

5.4. Chapter Summary

Thematic data analysis tools by Braun and Clarke were used, upon the analysis of data, three major themes in the study were documented. The themes were acquired from classifying patterns and have a closer look at them to find connotations and connections. The connotations were

informative in connecting the parents with children with disabilities and their human capabilities in Kraaifontein and Fisantekraal. The findings of the study indicated most parents can take care of their disabled children regardless of the multiple challenges they are faced with in areas that they live in. The findings showed that parents or caregivers of children with developmental disability' health (physical and emotional) and employment status are directly influenced by the condition of their child. The literature review supported the findings in every theme and sub-theme, while the theoretical framework underlined the human capabilities of parents or caregivers taking care of the disabled child.

CHAPTER SIX

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

6.1. Introduction

This is the final chapter of this study, and it focuses on summarising and concluding the research study. Recommendations of the study, as well as areas for future research, were discussed in this chapter. The present study explored the human capabilities of parents/ caregivers of children with developmental disabilities. The results of this study were presented and discussed in the preceding chapter. This chapter thus integrates the data gathered throughout the study with the view to provide conclusions based on the objectives of the study. The study was conducted qualitatively with the use of interviews to gather data that answers the research questions presented in the initial chapter of the study.

6.2. Summary of research findings

This study sought to explore the bodily health and bodily integrity capability of parents and/ caregivers with children with developmental disabilities. Bodily health and bodily integrity capabilities entail good health, adequate nutrition, adequate shelter, and the ability to move from place to place freely. The participants reported that they are not adequately nourished and do not have adequate shelter since they are not employed. Hence, they do not afford to live a healthy lifestyle. The results also show that the participants are having challenges with taking their children to the hospital for check-ups since they do not have decent transport. It is also a challenge for the participants to travel with the child which will result in the parents/ caregivers being confined to the house all day long to avoid the challenges of moving around with the child. Due to the children's disability, most of the participants argued that they do not have a stable emotional state

because they are constantly worried about the future of their children. Some of the parents/ caregivers were diagnosed with mental health-related illnesses such as high blood pressure.

Also, this study set out to explore how the government assists parents and/ caregivers of children with developmental disabilities in enhancing their human capabilities. The study findings show that some initiatives are in place in the studied areas that are meant to assist parents/ caregivers of children with developmental disabilities. The participants stated that the support they get from the government is the disability grant and the food assistance they receive through the Department of Social Development. In as much as the participants stated that they receive assistance from the government, some of the participants are not receiving anything from the government even the disability grant. Those that are receiving assistance argue that the assistance is not enough to cater to the needs of the child which will consequently make it difficult for the parents or caregivers.

Furthermore, this study also wanted to explore the programmes available to promote the freedoms and/or opportunities for parents of children with developmental disabilities. The results of the study indicate that some programs are available for caregivers with children with disabilities within the studied communities. The programs that are in existence include support groups, online programs, the school program, and counseling. These programs or services promote opportunities for the parents/ caregivers to access information and emotional support which is essential for their emotional health.

6.3 Chapter summary

This chapter is the final chapter of the study, and it is a build-up of the preceding chapter which focused on whether the objectives of the study have been reached and how they have been reached, and what it means. The study had the following three objectives:

1. Explore the bodily health and bodily integrity capability of parents and/ caregivers with children with developmental disabilities.
2. Explore how government assists parents and/ caregivers of children with developmental disabilities in enhancing the human capabilities of parents.
3. Explore the programmes available to promote the freedoms and/or opportunities for parents of children with developmental disabilities.

The first objective was achieved by exploring the bodily health and bodily integrity of parents or caregivers with children with developmental disabilities. The objectives have been achieved by conducting semi-structured interviews with parents and caregivers of children with developmental disabilities in Kraaifontein and Fisantekraal to explore their bodily health and bodily integrity. This tool was mainly used to obtain a sense of the participant's perception of the human capabilities of parents with children with developmental disabilities. The study looked specifically at both bodily health and bodily integrity and different views and experiences were found and further explored in chapter five. A qualitative study of an explorative descriptive nature by Muller-Kluits and Slabbert (2018) that had an aim to explore and describe the caregiver burden as experienced by family caregivers of persons with physical disabilities specified that caregivers frequently put a low priority on their health linked to that of their children with disabilities. The study uncovered that because caregivers focus on caring for the person with the disability, they are more likely to rank their own health needs very low.

- The second objective of the study was achieved by exploring how government assists parents and/ caregivers of children with developmental disabilities in enhancing the human capabilities of parents. This objective was achieved also through semi-structured interviews of parents and caregivers with children with disabilities. Through interviews conducted on the current study, it is evident that caregivers get food assistance from the government. However, the participants

for the current study argue that the food assistance they get is not sufficient as they are only given a few food parcels which do not consist of all the basic food commodities. Also, findings from Muller-Kluits and Slabbert (2018) further validated that parents of persons with disabilities characterised numerous barriers to accessing resources. Difficulties involved low prioritisation of these needs and lack of time, deprivation of relief times, lack of competent or knowledgeable substitute caregivers. Some parents with young children were unwilling to use relief care because they considered it their responsibility to look after their children themselves and were not willing to involve other people in the caring.

- Lastly, the third objective was to explore the programmes available to promote the freedoms and/or opportunities for parents of children with developmental disabilities. It is highlighted by the National Integrated Early Childhood Development Policy (2015) that the family caregiver must be offered the appropriate provision of community-based support services. Thus, Muller-Kluits and Slabbert (2018) noted that caregivers of people with physical disabilities required more time for themselves for relaxation. Therefore, a wish for additional help to relieve the strain of caregiving was conveyed by some caregivers in this study. They desired to have day-care centers, where they could take their grown-up children, which could allow them some spare time to do whatever they needed to do. As a result, the current study has also specified that the caregivers of children with developmental disabilities cope better with the assistance of community-based support or support groups in their areas where they will share their experiences with other caregivers of children with a similar disability. However, the support groups are not found in all the communities or some caregivers of children with developmental disabilities are not aware of the availability of the support groups. Most of the study participants claimed that there are no support groups for caregivers with children with disabilities in their areas.

The semi-structured interviews employed in the study made it achievable for the researcher to gain insight into understanding the views, reasons, and purposes for the specified research theme. As cited by Vernon-Dotson (2013) that the tool of research in qualitative research is the human mind. The qualitative research method makes use of interviews, focus group discussions, observations and re-examining the relevant literature. In qualitative research, the main intention of the researcher is to appreciate and understand the situation under investigation, primarily from the participant's and not the researcher's perspective. The collected data, attained from the different participants were examined, from which three main themes emerged that were discussed in detail in Chapter Five. Literature and theory were used to substantiate, explain, compare, and contrast the findings of this study. The results on the human capabilities of parents with children with disabilities in this study indicated that indeed parents of these children experienced different types of negative experiences because of their children's condition. It has also been revealed that because of having a child with a disability, most of these parents are not working as they must take care of their children. This in turn has a great impact on increased levels of poverty and negatively impacts the parents' ability to raise the child.

This present chapter provided a summary of the study findings of the objectives of the study. An application of the theory and the limitations of the study will also be incorporated in this chapter. Since the collected data was analysed and discussed, the conclusions that were drawn for the findings were presented in this chapter. Recommendations of the study that will help in enhancing the human capabilities of parents/ caregivers of children with developmental disabilities were also presented in this final chapter of the study. Lastly, the study proposed areas for future research on the human capabilities of parents/ caregivers of children with developmental disabilities.

6.4. Application of the Human capabilities' theory

The study made use of the human capability theory by Martha Nussbaum (2011). The theory was chosen against Amartya Sen's version of human capability because it is the best suitable theory in that it better explains the phenomena of exploring the human capabilities of parents with children with developmental disabilities as mentioned in Chapter Two of this thesis. The theory has 10 central capabilities but for this study, only two of the capabilities were chosen because of the direct correlation to the topic. The combined capability was also applied in the study to further explore the human capabilities of parents with children with developmental disabilities. The employed human capability theory for a South African context, as described in the discussion chapter, may be helpful in analysing other human capabilities of parents within the South African context. Further application of this theory may happen with other participants such as family and close relatives and or teachers who have direct of everyday contact with children diagnosed with disabilities. The influences described to influence parents' or caregivers' experiences in South African homes may apply to other contexts and parenting/caregiving situations.

The employed human capabilities approach for a South African context expands to present human capabilities literature. Since of there is a lack of relevant previous studies, it is apparent that there is a gap in the research field (Muller-Kluits & Slabbert, 2018). For instance a study by (Muller-Kluits and Slabbert (2018) mentioned that a study of this nature is therefore beneficial in enabling the social work profession to gain a better understanding of the experiences of family caregivers of persons with physical disabilities. This study is adding to the South African literature on human capabilities, as it was previously highlighted that parents, professionals as well as academic researchers have maintained that families of children with disabilities go through rare challenges because of their children's disabilities (Muller-Kluits & Slabbert, 2018) Although aimed at the South African setting, the approach might be relevant to other populations, where exploring human capabilities of parents or children with or without disability.

6.5. Limitations of the study

To discover and be aware of this quite unknown phenomenon of disability care in SA it is essential to interview many participants perhaps multiple times. This would fully allow general themes to occur (Abrahams & Rowhani, 2015). Despite this, the opportunity of this Masters' project allowed for a quite small sample of 11 participants who were only interviewed once. This means that some important themes may have been lost or not properly developed. Another limitation is that the phenomenon explored cannot be generalized to all populations. This is since the sample is small, not randomly selected, and is not representative of everyone in disability care.

Limitations in the study were indicated in the demographic information of the participants, as none of the participants was a mother and father figure caregivers or both parents participated in the study. The following were the identified limitations of the current study:

- The aim of the study was to interview both parents, however, there was only one parent available of which mainly female single parents or caregivers. Should both parents or caregivers or more male caregivers have been present during the study, varying information, and understandings about the human capabilities of parents or caregivers with children with developmental disabilities would have been encountered. Regardless of this, data saturation was attained via the data given by the participants and seems to sufficiently reveal the human capabilities and experiences of these parents and caregivers.
- Research done before has indicated that disability is linked with the socio-economic background (poverty), and even though the study did not specifically aim to explore the experiences regarding social class, the findings of this study have shown that almost all the participants were not formally employed due to the disability of the child.

- The study was only limited to parents of children with developmental disabilities. This means that only parents of children with developmental disabilities took part in the study not all other different types of disabilities.

6.6. Recommendations

This section of the study presents the study recommendations. The recommendations were made based on the aim of the investigation. The recommendations were based on the outcomes of the research findings and suggestions from the study participants. The following recommendations were made for this study.

6.6.1. Establish and strengthen support groups

There is a need for both the government and Non-Governmental Organisations operating within the Kraaifontein and Fisantekraal areas to develop and strengthen support groups for parents/ caregivers of children with developmental disabilities. This will assist the caregivers with emotional support from others with whom they share similar situations. The caregivers will learn and share their experiences with others. The support groups' facilitators can also engage experts who can educate the parents/ caregivers on how they can care for their children with a particular disability. This will increase the parent's or caregivers' knowledge regarding the type of disability of their child and how best they can assist him/ her to live a more productive life. Expert services can be drawn from pediatric doctors, social workers, and psychologists.

6.6.2. Sustainable income-generating projects

The study found that many of the participants are unemployed and cannot be employed because they must be always available at home taking care of their children who need their support. Thus, this study recommends the need for the establishment of sustainable livelihood projects which can be operated from home so that the caregivers can have a stable source of income to sustain

themselves and their children. This will go a long way towards curbing inadequate food challenges and poor health. It will also lessen emotional stress since the caregivers will be having a source of income.

6.6.3. Care centers

This study also recommends the establishment of care centers for children with disabilities where parents/caregivers can leave the children during the day under the care of trained personnel. This will enable the parents/ caregivers to work during the day so that they earn an income and not only rely on the government disability grant.

6.7. Areas for future research

There is a need for further research on the human capabilities of parents of children with disabilities since this study did not focus on all capabilities. A more extensive study can therefore be conducted focusing on all the human capabilities presented by Nussbaum. This study was purely qualitative; hence, a similar study can be conducted on a broader scale utilizing a mixed-method research approach to obtain rich data from a large sample that can be generalized. Also, another study can be conducted to investigate the coping mechanisms of caregivers of children with disabilities.

6.7.1. Application of Urie Bronfenbrenner's theory

For further research, the use of Bronfenbrenner's theory is recommended to explore a child with developmental disability's development within the context of the system of relationships that form his or her environment. As noted in the literature chapter that the environment has a huge impact on disability as disability and poverty have a huge correlation. Therefore, the study further recommends the employment of both the human capabilities with the inclusion of the Ecological systems theory. Future research could, therefore, make use of the Ecological Systems Theory because it maintains that an individual's development suggests the influence of several

environmental systems (which includes the microsystem, mesosystem, ecosystem, macrosystem, and the chronosystem) (Elliott & Davis, 2020). This means that all the above-mentioned systems can have an influence on the human capabilities of parents with children with disabilities. Bronfenbrenner's notion is that genetic material does not make complete traits but correlates with environmental involvements to influence the developmental outcomes. This way of thinking allows an individual to recognize that many characteristics that are attributed mostly to heritability (such as height) can be impacted by environmental systems (Elliott & Davis, 2020).

6.8. Conclusion

This study explored the human capabilities of parents/ caregivers of children with developmental disabilities. Basing on the study findings presented in the presenting chapter, this study concludes that the parents/ caregivers of children with developmental disabilities do not have strong capabilities because of some underlying factors such as unemployment. This negatively affects the parent's or caregivers' capability to care for their children with disabilities. Thus, there is a strong need to strengthen the caregivers' support systems since individuals do not live in isolation. If there are strong family and community ties, the capabilities of parents or caregivers of children with disabilities are likely enhanced. In as much as the government through the Department of Social Development is assisting in the form of food parcels and disability grants, these forms of assistance are not sustainable. Therefore, this study concludes that there is a need to shift from remedial or welfares assistance and focus more on developmental practice which ensures the sustainability of interventions.

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APPENDIX 1: Information Sheet



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INFORMATION SHEET

Project Title: An exploration of human capabilities of parents or caregivers with children (0-8 years) with developmental disabilities.

What is this study about?

This is a research project being conducted by Lumka Magidigidi at the University of the Western Cape. We are inviting you to participate in this research project because you are a parent of a child in early childhood with a disability. The purpose of this research project is to explore the parental capacity of parents and/ caregivers with children with developmental disabilities and promote parenting skills that will help find ways to ease the burden for parents who find it hard to cope with raising a child with a disability and ensuring the developmental needs of the child.

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

You will be asked to do an audio-recorded interview that will take about 20-40 minutes. The questions will be asked using English or isiXhosa language. The study will be conducted in resource constraint areas of the Western Cape mainly Kraaifontein and Fisantekraal location since more participants are found in these areas. The interview will only be done once per parent. The

interview questions will include questions about the things that parents do to make sure the child's needs are met, how the condition of the child has affected the parent's life, and so forth.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, the surveys are anonymous and will not contain information that may personally identify you". For coded identifiable information, state the following, if applicable (1) your name will not be included in the interviews and other collected data; (2) a code will be placed on the survey and other collected data; (3) through the use of an identification key, the researcher will be able to link your survey to your identity; and (4) only the researcher will have access to the identification key.

To ensure your confidentiality, your contribution will not be made available to other people. This means that all your contribution will be kept safe at all times by using password-protected computer files and ensuring that the notes that will be taken down during the interview are stored in locked storage. If we write a report or article about this research project, your identity will be protected.

Following legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. *In this event, we will inform you that we have to break confidentiality to fulfill our legal responsibility to report to the designated authorities.*

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during

the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

The benefits to you include more information with regards to where to go for assistance with the disabled child and how to cope with raising a child with special needs and assist with programs available to assist parents or caregivers.

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

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

What if I have questions?

This research is being conducted by Lumka Magidigidi from the Child and Family Studies at the University of the Western Cape. If you have any questions about the research study itself, please contact Lumka Magidigidi at 26220, Caka Street, Wallacedene, Kraaifontein, 7570/
3817846@myuwc.ac.za

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

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This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Humanities and Social science Research Committee

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APPENDIX 2: Informed Consent



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INFORMATION SHEET TEMPLATE

ADDITIONAL GUIDANCE FOR SPECIFIC ISSUES

Informed Consent

Informed consent is a process, not just a form. The information must be presented to enable persons to voluntarily decide whether or not to participate as a research subject. Therefore, informed consent language and its documentation must be written in language that is understandable to the people being asked to participate.

Research Involving Minors

For research involving individuals under the age of 18, including a Parental Permission Form to ask parents for consent to the participation of their child and an Assent Form to ask the minors if they agree to participate in the research, depending on whether the children are capable of asserting. The Parental Permission form should contain all of the elements of the sample consent form. However, the parental permission form should be written in language appropriate for parents granting permission for their child's involvement rather than as though they will be participating (e.g. we are inviting your child to participate the risks to your child's participation included). When

determining whether the children are capable of assenting, take into account the ages, maturity, and psychological state of the children involved. Assent forms should be written in age-appropriate language.

Research Involving Individuals with Impaired Decision-making Capacity

Using the Informed Consent Form Template, prepare a consent form to ask the research subject's authorized representative for consent to the participation of the research subject. Prepare an assent form to ask the research subjects if they agree to participate in the research, depending on whether the subjects are capable of asserting.

When determining whether the subjects are capable of assenting, take into account the decision-making capacity of the research participants.

Audio taping/Videotaping/Photographs/Digital Recordings

This research project involves making audiotapes of you. The audiotapes are a means of collecting valuable information needed for the study. Only the chief investigator and the supervisors will have access to the recordings. The recordings will be safely stored in the drive to and passwords will be used to access the drive.

___ **I agree to be [audiotaped] during my participation in this study.**

___ **I do not agree to be [audiotaped] during my participation in the study**

APPENDIX 3: Consent form



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CONSENT FORM

Title of Research Project: *An exploration of human capabilities of parents or caregivers with children (0-8 years) with developmental disabilities*

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 audio-recording and I agree to participate in 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.

Participant's name.....

Participant's signature.....

I agree to be audio-recorded.....

I disagree to be audio-recorded.....

Date

APPENDIX 4: Interview Questions



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INTERVIEW QUESTIONS – English

Bodily health, Bodily integrity, and Combined capability interview questions

Age:

Gender:

Highest educational level:

Marital status:

Location:

Gender of the child:

Age of the child:

Bodily health

- **Good health**

1. Can you explain to me what good health means to you? **Probe:** What are the things that you do or eat that makes you a healthy person? **Probe:** What do you do to make sure that your physical, mental and emotional health is taken care of?
2. Do you think that you are living a healthy lifestyle? **Probe:** what are the things that you do or eat that makes you think that you are living a healthy lifestyle? Why?
3. Can you describe the disability of your child, does the disability of your child affect your physical and emotional health? Why and how?
4. What do you do to ensure that your body stays healthy (physically/ emotionally or spiritually) all the times? **Probe:** How is that beneficial to your body? Explain.
5. How often do you go to the doctor for yourself? **Probe:** Can you explain to me what would be the reasons for your visit?

- **Adequately nourished**

1. Can you explain to me what does healthy eating mean to you?
2. Which type of meals do you eat daily? **Probe:** What do you eat for breakfast, lunch, and supper? Why do you eat those type of meals?
3. Do you think that the food you eat daily is healthy? Explain why?
4. What are the kinds of things that you consider when buying food (i.e. nutritional information, price cost, accessibility, etc.) and why?

- **Adequate shelter**

1. Where do you currently live? With who?
2. Describe how is the environment of your house accommodates the disability of your child? The physical setting of your house? **Probe:** Is there electricity, bathrooms, and kitchen that are disability friendly? How many rooms? How is the sleeping arrangement?
3. Who is the owner of the house? **Probe:** Do you own a property of your own? If no why? If yes, who bought the house for you?
4. Will your child be able to do things on his/her own in the house without your assistance? Please elaborate or explain how?

Bodily integrity

1. How do you travel from place to place with your child? **Probe:** Which mode of transport do you use and how do you access the transport?
2. What mode of transport do you use when traveling with your child? Why?
3. Who is assisting you and your child when you are traveling? **Probe:** Where do you usually go to when you are traveling? Can you explain the type of assistance that you need when traveling with your child? How are your daily movements affected by your child's disability? **Probe:** How is your daily routine? What are the things that you do daily with your child from the morning until the evening?
4. Have you ever encountered any form of discrimination because of your child's disability? **Probe:** Did you somehow ever been judged, looked or treated differently or called names because of your child's disability? When? How?

Combined capabilities

1. Are you able to express your own views and thoughts without the fear of being stopped from talking? Where do you express these views? When?
2. Do you ask for help or assistance when required? **Probe:** what kind of assistance do you require most times? What is the response to your request?

3. Are you currently working? **If yes**, how do you handle work and taking care of your child? **If no**, why?
4. Can you explain what kinds of support you and your child are you getting from your community? Probe: What impact does that have on you or your child?
5. Which opportunities are available for parents with children with disabilities in your area? Probe: Is there any governmental or non-governmental programs/ organisations in your community specifically made for parents of children with disabilities? Probe: **If there are programs**, what are you gaining from these programs? **If there are no programs**, what kinds of programs would you require as a parent of a child with a disability and why?



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INTERVIEW QUESTIONS – IsiXhosa

Bodily health, Bodily integrity, and Combined capability interview questions

Iminyaka:

Isini:

Ibanga eliphezulu oluphumeleleyo:

Utshatile:

Igama lendawo ohlala kuyo:

Isini somntana:

Iminyaka yomntana:

Impilo ngokwasemzimbeni

- **Impilo Elungileyo**

1. Ndicela undicacisele ukuba ngokolwazi lwakho ukuba yintoni impilo elungileyo? Probe: zintoni ozityayo okanye ozenzayo ezinkwenza ukuba ubengumntu osempilweni? Probe: So zintoni oye uzenze ukuqinisekisa ukuba impilo yomzimba, ingqondo kunye nasemphefumplweni wakho ikhathalelekile?
2. Ingaba ucinga ukuba uphila impilo esempilweni? Probe: Zeziphi izinto ozenzayo okanye ozityayo ezibangela ucinge ukuba uphila impilo esempilweni? Ngoba?
Ingcaciso: Ingaba oGqirha bamfumanisa ukuba unesisifo emveni kokuzalwa apha esbhedlele?

3. Ndicela undicacisele ngokukhubazeka komntana wakho, ingaba ukukhubazeka komntwana wakho kuyayichapazela impilo yakho ngokwasemzimbeni okanye emphefumleni? Ikuchaphazela kanjani?
4. Yintoni oyenzayo ukuqunisekisa ukuba umzimba wakho uhlala esempilweni (ngokwasemzimbeni, engqondweni nasemoyeni) ngamaxesha onke? Ingaba ikunceda kanjani lonto? Cacisa.
5. Uye uye kangakanani kwaGqirha xa use wena? Ndicela undicacisele ukuba uqhele ukuya xana uyokwenzani kwGqirha?

- **Ukutya okwaneleyo**

1. Ndicela undicacisele ukuba kuthetha ukuthini ukutya ngokusempilweni ngokolwakho uluvo. uphando: Ubuyivaphi mhlawumbi le ncukacha? Ngubani okuxelele ngokutya okusempilweni?
2. Kukutya ukunjani okutyayo mihla le? Yintoni oyityayo ukusukela ekuseni, emini kunye nasemalanga? Kutheni usitya ezi zidlo?
3. Ucinga ukuba ukutya okutya mihla le kusempilweni? Cacisa ngoba kutheni?
4. Ziintoni oye uziqwalasele okanye ozijongayo xa uthenga ukutya (umzekelo: amaxabiso, ukufumaneka lula okanye izondlo) cacisa ngoba?

- **Indawo yokuhlala efanelekileyo**

1. Uhlalaphi ngoku ngalomzuzu? Uhlala nabani?
2. Cacisa ukuba isimo sendlu yakho sisilungiselela njani isigulo somntwana wakho? Indlela eme ngayo indlu. **uPhando:** ingaba ukhona umbane, igumbi langasese, igumbi lokutyela elilungele abakhubazekileyo? Mangaphi amagumbi? Ithini imeko yokulala?
3. Ngubani umnikazi wendlu? **uPhando:** Ingaba unayo eyeyakho indawo? ukuba hai ngoba? Ukuba ewe ngubani owakuthengela londlu? **uPhando:** Nilala njani? Ingaba nilala kumagumbi ahlukileyo? **uPhando:** Kengoku awunayo eyeyakho indlu?
4. Angakwazi umntwana wakho ukuzenzela izinto apha endlini ngaphandle koncedo lwakho? Ndicela ucacise njani?

Ingqibelelo yoMzimba

1. Utyelela njani nomntwana wakho kwindawo ngendawo? Usebenzisa oluphi uhlobo lwesithuthi kwaye lufumaneka njani?
2. Loluphi udidi lwesithuthi othi ulusebenzise? Yintoni isizathu soko?
3. Ngubani okuncedisayo xana uhamba nomntwana wakho? **uPhando:** Nibe nisiyaphi xa nihamba nomntwana wakho? Loluphi uncendo oludingayo xa uhamba nomntwana wakho? **uPhando:** Luphazamiseka njani uhambo lwakho lwangemihla ngemihla ngenxa yemeko yomntwana wakho? Luba njani uhambo lwakho lwemihla ngemihla?
uPhando: Ingaba umnyakazo wakho wemihla ngemihla uchatshazelwa njani kukukhubazeka komntwana wakho? Ziintoni oye uzenze kunye nomntwana wakho ukusukela ekuseni ukuya kutsho emalanga?
4. Wawukhe wangomnye wamaxhoba okucakucalulwa ngenxa yokukhubazeka komntwana wakho? Probe: Wawukhe waphatheka kakubi okanye waphathwa ngendlela engeyiyo ngenxa yemeko yomntwana wakho? Nini? Njani?

Combined capabilities

1. Ingabe uyakwazi ukuthetha okanye ukuphalaza imbilini nemibono yakho ngapahndle koloyoko lokunqandwa ukuba uthethe? Ingaba uziveza phi ezi mbono zakho? Nini?
2. Ingaba uyalucela uncendo xa uludinga? Probe: Luncendo olunjani oye uludinga kumaxesha amanintsi? Uye ulufumane oluncdedo?
3. Ingaba uyaphangela? Ukuba ewe, umelana njani nomsebenzi uphinde ukhathalele umntwana wakho? Ukuba Hayi kutheni ungaphangeli?
4. Cacisa ngenxaso wena nomntwana wakho eniyifumanayo kule ndawo nihlala kuyo? Loluphi ugalelo loluncedo kuwe nakumntwana wakho?
5. Ingaba zikhona iingqubo zikarhulumente okanye ezasekuhlaleni ezenzelwe abazali babantwana abakhubazekileyo kulendawo uhlala kuyo? Probe: ukuba zikhona, yintoni uyixhamlayo kwezi nkqubo? Ukuba azikho, ziinkqubo ezinjani ongazidinga njengomzali womntana okhubazekileyo? Ngoba? **uPhando:** Ukuba azikho, ziinkqubo ezinjani ongazidinga njengomzali womntana okhubazekileyo? Ngoba?

APPENDINX 5: Ethics Letter



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27 August 2019

Ms L Magidigidi
Social Work
Faculty of Community and Health Science

Ethics Reference Number: HS19/6/44

Project Title: An exploration of human capabilities of parents with children (0-8 years) with disabilities

Approval Period: 27 August 2019 – 27 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.

A handwritten signature in black ink, appearing to read 'Patricia Josias'.

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

HSSREC REGISTRATION NUMBER - 130416-049

APPENDIX 6: Editorial letter

+27 72 594 8848

mawokomayi@gmail.com

Date:02/09/2021

RE: TO WHOM IT MAY CONCERN

This letter serves to confirm that I have edited a Masters dissertation titled:

*AN EXPLORATION OF HUMAN CAPABILITIES OF PARENTS WITH
CHILDREN (0-8 YEARS) WITH DISABILITIES*

By

MAGIDIGIDI LUMKA

Student Number: 3817846

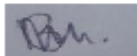
studying at the

UNIVERSITY OF THE WESTERN CAPE

I carefully read through the dissertation, focusing on grammatical errors and spelling mistakes.

Please do not hesitate to contact me for any queries.

Yours Sincerely,



Ms Mawokomayi

*Betina Mawokomayi, Msc Communication, (University of Fort Hare) B.A. Hons, Lit. & Media Studies
(University of Venda), B.A. Media Studies (University of Venda). Language & Writing Consultant (University of
Fort Hare).*