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Exploring the Lived Experiences of Parents of Children with Cognitive Learning Barriers at uMkhambathini

By

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DEDICATION

I dedicate this master's thesis to my late parents Jeffrey Mboneni Ngcobo and Zandile Beauty Gwala. You left too soon but we remain connected by blood and your graceful spirits. I continue to extend my sincere appreciation of the love and support I have constantly received from my surviving family. May your prayers continue to strengthen the symbol I am becoming.

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ABSTRACT

The ethnography that was embarked on in completing this paper aimed at collecting the emic perspectives of parents of children with cognitive learning barriers at uMkhambathini. The main objective was to understand their lived experiences as parents of children living with disabilities. The hallmark for doing an anthropological study is undertaking ethnography while being highly cognizant of holism as a principle in anthropological research; such consideration drives researchers to consider all important details that contribute to the phenomenon that is being studied. This was the manner in which the study was completed, and it was brought to an understanding that socio-cultural contexts of parents in the topic have not received much attention in the public domain, especially in rural areas like uMkhambathini where the study was conducted; although it should now receive essential consideration, especially if the makers of policy in the public sector have to achieve adequate and uncompromised inclusion whether in learning or designing appropriate psycho-social support initiatives for parents or their children living with disabilities in an inclusive environment. A total of fifteen (15) parents of children living with cognitive disability as a learning challenge in question were purposively sampled from Asizenzele, Inkanyezini and Table Mountain Primary Schools. The findings were generated through in-depth interviews as well as focus group interviews which allowed parents to share their personal and collective experiences; this also helped the study to collect quality of these experiences. Parents responded to sixteen (16) research questions and significant themes were generated following a thorough qualitative thematic analysis. Theoretical framework and the existing literature in the subject were used to analyse and anthropologically interpret experiences of parents. The socio-cultural perspective is the quarry in which individual problems related to the topic exists; in this breath, government must also design, implement and promote public activism to safeguard education and socialization of people living with disabilities in general.

Keywords/phrases: Parents, Children with Cognitive Learning Barriers, Identity, Disability, Education, Inclusive Education Policy, Intervention, Rural Area, Lived Experiences, Socialization, Social and Educational Exclusion.

ACRONYMS

Category B Municipality- Municipality that shares both municipal executive/legislative authorities in the area with a category (C) municipality within whose region it falls.

CLD: Cognitive Learning Disability

LD: Learning Barrier

LD: Learning Disability

KZN: KwaZulu-Natal

PMB: Pietermaritzburg

EFA: Education for All

The UNICEF: The United Nations Children's Fund.

UNESCO: The United Nations Educational Scientific and Cultural Organisation

CFEA: Conference on Education for All

HOD: Head of Department

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Chapter 1

Introduction and Background

1.1 Introduction

Many scholars such as (Battles 2011) and (Roll-Pettersson 2001) have examined the socio-economic issues that trouble parents in most parts of the world and concluded that their vulnerability is mainly within the context of patriarchy, gender-based-violence, unemployment and rights to sexual and reproductive health (Rogers 2007). A holistic analysis of the experiences of parents who are raising children living with disabilities is lacking in the abundance of writings addressing parent's and parenthood issues. The aim of this thesis is to present the experiences of parents who raise children with a cognitive disability, drawing largely on anthropological theoretical lenses and research methodologies. This chapter presents the research background by providing the justification, the research problem and explaining the relevance of this research interest in anthropology. It further outlines the rationale, defines key concepts and briefly discusses the theoretical lenses utilized in the study, the research objectives/questions, and the structure of the thesis.

1.2 Statement of the problem and its relevance in anthropology

As postulated by Reid-Cunningham (2009), the disciplinary dimensions of social, cultural and medical anthropology have enriched the understanding of disability as part of human living. It is said that anthropological interpretations of disability have featured concepts of "the other", deviance and stigma that could inform our broader interpretation of human behaviour in the social ecology (Reid-Cunningham 2009). The scholar went on to say that, anthropology studies humanity and highly relies on cultural relativity as an organizing principle. The present study is situated in the socio-cultural aspect of anthropology. This aspect of anthropology details human experience which is inclusive of status, religion, law, stigma and deviance. This study takes interest in the embedment of disability in social realities, particularly, the caring and nurturing of children with cognitive learning barriers. The Human Rights Watch defines cognitive disability in persons as presenting with significant characteristics of limitations in mental functions such as learning, reasoning, problem solving and adaptive behaviour, these limitations reflect in efforts to acquire social and practical skills (Human Rights Watch 2015).

Biological anthropologists observe that most families, whether nuclear or extended, have members who are living with a particular disability which remains a life condition that is

unfamiliar to most communities (Reid-Cunningham 2009). This lack of familiarisation often leads to discrimination, exclusion and alienation of those with a particular disability. Anthropologists further observe that many societies do not recognize people with disability as human beings who should enjoy equal human rights, decent care, support and recognition. Studying human disabilities and the experiences associated with it is not new in anthropology (Roll-Pettersson 2001).

Battles (2011) argued that disability is an imperative human journey throughout cultures and how it impacts families must be studied consistently in anthropology as a discipline that is fascinated with the analysis of developmental aspects of human living. This study was informed by this conception of the discipline of anthropology. Shirley and Fedrak (2017) argued that the discipline of anthropology must assume studies about experiences of humankind with a holistic approach. Through this approach, anthropologists must try to trace the root causes of otherness which has been the case with disability in human societies. Anthropology is the social science that studies human groups and their behaviour, their interactions with each other and with the material of the environment. The context of this study is the experience of parenting of children with cognitive learning disabilities. Hassal et al (2005) assert that many studies have demonstrated that parents of children with any form of disability are likely to experience significantly higher levels of parenting stress than parents of "non-disabled" children. Many of such studies have not clearly detailed the life experiences of parents of children living with cognitive learning disability (CLD) in uMkhambathini. This is a gap in literature that has existed for a long time and which this study aimed to bridge.

The problem that has prompted the undertaking of this study is that uMkhambathini community, as a rural community in uMsunduzi local municipality in the province of KwaZulu-Natal (KZN), has children with cognitive disability. This learning barrier has led to their exclusion from accessing formal education. I observed that some of these children attend early grades in mainstream formal schools but eventually get excluded as they progress because of their disability. Being excluded from progressing to other schooling grades and not attending a special school appeared to be a violation of their right to education. This study is not focused on the children with cognitive disability, but on their parents and how they manage the challenges posed by raising such children who face education exclusion and other social difficulties. It will be relevant to have an anthropologically documented access to their experiences especially because there are

underlying reasons or meanings in sending their children to mainstream/formal schools. As a growing scholar in the discipline of anthropology, I have committed my research skills and I have employed theoretical perspective within the field to study the problem in question. With this effort I aim to find and document the unknown experiences of parents who have children that are living with learning barriers. I am hopeful that this study will contribute towards the revision of policies or in the framing of public policy issues to change the lives of people for the better. As such, the findings of this study will contribute a holism outlook of special education and adequate inclusive support in in the future, especially in areas such as uMkhambathini.

Kang, Choi and Jin Ju (2016) observed that the birth of a disabled child is said to provoke dispute and self-blame within the family and society. Parents are not socialized to raise a disabled child as they normally would not anticipate giving birth to a disabled child when they plan to have children. Although some parents know about the disability of their children while they are pregnant, they usually pray against it up until the day of delivery. When the baby is confirmed from birth or is diagnosed with symptoms of a disability as they grow, parents become stressed and are expected to learn or adapt to the disability condition confirmed on their children (Roll-Pettersson 2001). Kumar (2016) also noted that the journey of loneliness becomes their parenting journey. They are questioned, ill-treated and not supported by their partners, families, friends and other societal structures such as churches, schools and health institutions (Kumar 2016).

The disability of their children does not present them with other choices but to become the first call of support for their children who may not know what is happening in their lives. The parenting journey becomes gloomy as parents suffer from endless sorrow and hopelessness, depression and guilt for their children (Battles 2011). Parents encounter various demands and restrictions which have not reached the attention of public policy. Their children grow to experience many forms of exclusion and isolation from the services that other children have access to, enjoy or celebrate.

An internal debate that parents embark on is to ask questions to which, most times, they do not have the immediate solutions for, and hope for the situation to change by the power of beliefs or any other natural way that might not be known. Such questions would include where will the child go for educational empowerment? How will the child be conventional and cope whilst attending school? How will they guard their identity or how will they prepare

him or her to accept such identity? (Bingham 2017) stated that parents in Cape Town, where she conducted her study, went through a journey of self-blame and visible, period of stress daily, exhausted and burned out, lonely, feel unappreciated and uncared for by their families, angry and frustrated, worried, anxious and fearful, shamed and embarrassed as well as stigmatised and marginalized in the community, which also hinders the social acceptance of their children.

Oti-Boadi (2017), said that, raising or giving birth to a child with any form of disability in any way was often described as depressing. They argued that it presents a psychological challenge such as anxiety and physical signs and symptoms of depression for most parents. Parents of learners with disabilities put in greater effort and dedicate more of their free time to meeting the needs of their children. Families are expected try their private means with small salaries that they might be earning to adapt or undertake new roles of meeting the unique desires of the child, especially on their education journey. Thus, this study aimed to look into the depth of such experiences.

Taderera and Hall (2017) also noted that when parents discover that their child have a cognitive learning disability, they are subjected to experiences and lifestyle that is frequently changing, filled with overwhelming modes of socialisation. Reid-Cunningham (2009)) observed that disability anthropologists such as Robert Murphy described human beings with disabilities as confined human beings because their intellectual conditions or bodies prevent their ability to acquire self-reliance, independence, and non-public autonomy and they locate themselves as socially excluded. He further argued that, people with disabilities are taken as objects of desperate care now, not as whole human beings who have to be trusted with opportunities to make their lives better.

In the article titled Anthropological Theories of Disability, Reid-Cunningham (2009) asserted that the discipline of anthropology has supplied a theoretical context for the learning on disability. Ethnographic research in anthropology has shown that parenting gives one a social or symbolic identity, position and status over their children. The disabled individual can be socially recognized as the "other". Such social, symbolic identities, roles and statuses from parents are sometimes overwhelming, especially when a guardian is faced with the responsibility of having to raise, accept and socialize a child with any form of disability. Reid-Cunningham (2009) also went on to note that anthropologists have found interest in

studying people with any form of disability because they are perceived as the "other," which in some way separates them from people who are not considered to have disabilities.

As postulated by Maccoby and Martin (1983), the disciplinary dimensions of social, cultural and clinical anthropology have enhanced the understanding of disability as a subdivision of human living. It is stated that anthropological interpretation of disability goes past standards of "the other", abnormality and stigma that ought to inform our broader interpretation of human behaviour in the social ecology. Anthropologists conduct research on, with, and about people and societies and especially relies on cultural relativism as a consolidating principle. This research is situated in the socio-cultural aspect of anthropology. This aspect of anthropology details human journey which is inclusive of their social status, religion, law, stigma and uniqueness. This study takes interest in studying the embedment of disability in social realities, particularly in caring and nurturing children with disability identity. This was assessed from the perspective of parents who shared their experiences for the purpose of this research.

Battles (2011) affirmed that anthropologists have continued to play a significant role in understanding disability in social and cultural contexts. Anthropological inquiries on disability are argued to have blossomed in the course of the 1980s, although as early as 1934, Ruth Benedict is said to have been listed as the first anthropologist to write about cross-cultural conceptions of epilepsy. Reid-Cunningham (2009) wrote that Lousie Duvalla was a medical anthropologist who inaugurated the Sub-Culture and Disability newspaper which proved to be the main source of information on disability for anthropological and other social science theories.

The works in the newspaper had the sole purpose of revealing the different faces of disability that challenged people in different societies in the past. This original study also aimed to form part of the body of knowledge that contribute to the valuing and normalisation of disability based on life history accounts of parents of children who are living with a cognitive disability. These ethnographic accounts were drawn from rural area where normal social living is impacted by the problems of disability (Reid-Cunningham 2009).

1.3 Rationale of the study
The problems associated with disability have been presented as multi-dimensional and as constituting a lot of weight on parents who raise children with any form of disability (Ritzema and Sladeczek 2011). South Africa has tried to adopt a variety of interventions to

curb the stresses of disability in the country including the Inclusive Education Policy. However, issues related to social exclusion and stigmatization of people with disability continued to persist. Hence, the undertaking of this research project with the aim of developing an adequate and reflective anthropological prototype to be used by educational policy makers in designing inclusive support for parents who care and raise children with cognitive disability. Investigating the depth of experiences of parents raising such children at uMkhambathini may create more awareness about these experiences and influence policymaking. Thus, this research study could assist in addressing relevant issues around restrictions and exclusions, especially in the education system.

1.3 Why the study sought experiences of parents instead of children

Although it has been said from the beginning of this chapter, I still found it necessary to re-emphasize that the study was not looking to learn about the experiences of children with cognitive disability. Prior to the approval of this study, a rapid search and review of literature indicated that psychologists and social workers have largely invested in research that focused on children with disability (Kumar 2016). A gap exists on the experiences of the parents whose parenting seemed to be different from other parents whose children are living without any disability. Anthropology is a discipline that is concerned with humans and human culture. In human culture parents are very important in their children's lives as they are holistically involved in the nurturing of their children from pregnancy (Reid-Cunningham 2009). The parent-child relationship is often considered to be the most enduring and significant relationship in one's life. Children's most import early relationships are with parents. Parents play critical roles in the lives of their children which involves nurturing the psychological and the psycho-social well-being of the child. Also, parents are not unaffected by any experience that their children go through and always wonder about the cause and endurance of these experiences.

This study recognises that parents have a strong bond with their children and should be given the platform to narrate their parenting journey and the struggles they are faced with on a daily basis. The study also recognised the importance of studying the depth of human experiences in order to understand them better, and mostly to attempt to find solutions where needed. The literature has little about interventions directed to help parents of children with cognitive disability cope with the associated challenges. Although scholars such as Kumar (2016) have written and highlighted the restriction to normal life experienced by parents who have children with cognitive disability; Kumar (2016) found that parents' narratives have been

overlooked in the process of designing support, which has led to the prevalence of problems of exclusion of their children in educational institutions and in social access. In the view of this study, the makers of policy regarding learning disability can learn and effect many changes from the feedback given by parents on their journey of caring for children with cognitive disability.

1.3.1 Constant Nurturing Involvement of Parents on their Children

Martin (2000) argued that parenting is a process of promoting and supporting a child's physical, emotional, social, financial, and intellectual development from early childhood to adulthood. Parents are constantly involved in the raising and socialization of their children, which impacts the development of the child's character and is responsible for shaping the child's cognitive and linguistic perceptions.

The position of a father or mother towards their children is of vital importance and parenting can be one of life's most joyful experiences as it brings new and sudden existence of "new normal life" to families. It can deliver great joy, love, pride, excitement and happiness for most parents (Bingham 2017). However, in the case where parents gave birth to a child with disability, life may require strength and resilience as it tests their parenting capabilities and sometimes creates frustrations. Sometimes, some parents feel that they are not being "good parents" and as a result can become resentful and violent towards the children or the whole parenting situation. In this regard, all parents no matter where they live or what their circumstances may be, need help and information about raising and coping with different parenting situations that they might be facing (Bingham 2017).

Maccoby and Martin (1983) and Gottfried et al (1998) in their respective publications stated that the role of parents in the lives of their children is of particular importance for the development of the children's personality. They further noted that the basic traditional roles of parenting are to nurture, educate and discipline children. The idea is that parents should focus on their children and aim for the maximum development and growth of their children. This in turn is believed to help the children achieve satisfactory biological, social, psychological and emotional development.

1.3.2 Nurturing Expectations Regardless of Disability Condition

 Maccoby and Martin (1983) outlined the requirements for the achievement of children's needs for maximum development. These include proper home environment, tolerant and positive socialization from an early age, positive change and improvement of conditions

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(Maccoby and Martin 1983). Parents have a responsibility to protect their children what to do and what not to do. These scholars further mentioned that to raise a child properly is not only limited to the provision of food, shelter and protection. It is also to teach and educate them, to shape knowledge and character, to prepare children to face the real world. Another role of parents is to make possible the learning of such actions as walking, talking, reading and writing. To facilitate the learning of these activities, a parent must have patience and understanding.

Furthermore, parents are involved in the life of their children as learners. This is when they have reached the school-going age and have enrolled into learning institutions. In this phase of a child's life, parents would want to see their children flourish, given a good start in their educational life and acclimatizing independently in the general school-livelihood regardless of their disabilities (Ritzema and Sladeczeck 2011). These are some of the roles that the study wanted to assess in the journey of parents of children with cognitive disability, as each phase of life of their children comes with its challenge. A parent is a person who is a biological mother/father or legal guardian, legally entitled to custody of a child, the person who is committed to fulfilling the obligation to be a parent (Ritzema and Sladeczeck 2011).

The main goal for parents is to provide the child with the best possible education. To do this, a parent ought to be a good observer and instructor for his or her child to understand the child's behaviours, moods and activities. Parents are expected to be models for their children and to take care of their daily experiences. Positive factors include praises, encouragement, calm conversations and responses and affectionate attention which help to build healthy emotions (Thompson and Pomerantz 2008). Parents should accept that each child is unique and must not compare their children with others especially when they observe any weaknesses. Parents are expected to help their children with being different and encourage their children to be unique.

Parents are expected to help their children learn to express their feelings and desires, and to help them develop healthy relationships. They ought to contribute to the emotional development of their children and keep them away from social experience that could negatively affect their emotional growth (Thompson and Pomerantz 2008). They also must take responsibility for developing positive self-esteem, a strong sense of security, confidence and ensure that their children always feel loved. Parents are encouraged to remain calm and emotionally supportive, as well as invest in teaching their children how to control and change

their thoughts, emotions and behaviour. This means that parents are responsible for understanding what the child reports directly or indirectly about their attitude and behaviour. Calm and persistent conversation helps children recognize their mistakes.

I.3.4 Why is it Necessary to Learn about the Experiences of Parents of Children living with Cognitive Disability?

The above assertions placed parents at the centre of their children's developmental stages which included the cognitive, sensitive, cultural and social aspects of a child's growth (Thompson and Pomerantz 2008). It has also been said that parents of children with cognitive disability do not get to have a normal way of helping their child acclimatize to these complexities of mental and social processes, as their way of parenting is ever-changing and dependent on a child's disability. Parents of children with cognitive disability are constantly faced with the duties of making and altering decisions on behalf of their children (Willingham-Storr 2014). Therefore, parents play a paramount influence on any phase of the development and future of their children. Cognitive disability can be a permanent condition and producing vast emotions. Parents who have children with this kind of disability are said to gradually adapt to the demands of parenting.

Their parenting and coping transitions have to be kept in check and necessary intervention must be made available to gradually teach them acceptance. Parents need to be trained to bear with any potential mental breakdown from the external factors that affect the education and socialisation of their children. Lastly, there is also a need to guide the decision-making of parents of children living with cognitive disability beyond home-based caregiving. As mentioned earlier in the chapter, parents have high expectations for their children and hold a very strong parental connection with their children which could consciously and unconsciously impact their decision-making. This may be seen in instances where children have reached school-going age and their parents need to make decisions about where they should be sent to for better cognitive development (Roll-Pettersson 2001). These are the necessary arguments that this study put forth to support the idea that the role and provisions for parents must not be lost in research and in the formulation of policy, especially regarding caregiving and education of children with cognitive learning disability (Willingham-Storr 2014).

Cognitive disability is complex and multi-dimensional. Some parents can read the behaviour of their children and take necessary steps to accept and make the best possible decisions for the betterment of their children's cognitive development. However, other parents find it

difficult to accept and to afford the necessary help for their children. The place of convergence is that parental experiences about cognitive disability will always vary and will remain a relevant subject to many parents and in relation with a particular social influence. All the necessary assistance must be made available by the department of education to help parents choose and or make proper choices for the education of their children; hence, the focus of this study on exploring the lived experiences of parents of children living with cognitive learning barriers.

1.4 Location of the Study

uMkhambathini is a rural community. It is in uMsunduzi municipality under the uMgungundlovu District of KwaZulu-Natal. The community is classified under the class B category of communities in the district. It is situated along the south-eastern periphery of the uMgungundlovu District. It is the second smallest of seven municipalities in the district. It is made up of seven wards, mostly rural in nature and considered under-developed. The study was conducted in three schools located in two of the seven wards (wards 4 and 5).

The schools are far from each other, separated by, at least, three villages. There are no special schools next to or within the location of the three ordinary schools where the sampled parents come from. The parents could be seen commuting in the morning and afternoon as they accompany their children to show care and protection. It is not every parent in uMkhambathini that is able to take their children to special schools in Pietermaritzburg town even if it may be necessarily needed; as many have resorted to sending their children to the ordinary public schools under the operative policy of inclusive education. Figure 1 below is a map showing uMgungundlovu District Municipality with all the Local Municipalities and the location of uMkhambathini where the schools are located in relation with Pietermaritzburg city:

Figure 1: uMgungundlovu District Municipality. *Source: Google Maps (2020)*

1.5 Research Objectives

A research objective is the specific aim of a study. It stresses the research focus on the identification and description of variables and terms in order to achieve the goals of the research study (Du-Plooy et al 2014). The research objectives for this study were informed by the perspectives of ecological theory and identity theory as these were the principal theoretical framework of the study. The research objectives of this study were to:

o Explore the lived experiences of parents of children with cognitive learning barriers in uMkhambathini.
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o Learn if such parents received any form of support in raising children with cognitive learning barriers, including individual, institutional support and the nature of the support.

o Learn about parents' views of the future regarding the learning condition and the situation of their children

1.6 Research Questions

The key questions were developed from the research objectives and in accordance with the theoretical framework that was used in the study. The key questions that were asked for the achievement of the research objectives were:

o What challenges do parents of children with cognitive learning barriers face due to the children's need for learning on daily basis?

o What kind of support do parents of children with cognitive learning barriers receive in raising and supporting their children?

o What opinions/views do parents of children with cognitive learning barriers have regarding the future of learning and the condition of their children?

1.7 Definition of Important Concepts

Parents: Taderera and Hall (2017: 2) defined a parent as "a person who is in custody of and take a series of actions to promote the development of a child".

Parenting: is a process of promoting and supporting the physical, emotional, social, spiritual and intellectual development of a child from infancy to adulthood (Burke 2008)

School: according to Hodges (2011), a school is an environment for carrying out the process of transmission of culture, including skills, knowledge, attitudes, values and particular behavioural patterns.

Parenting journey: is defined as related to providing parental care to a child and the steps that are taken by parents or a parent to understand and support the development of their children and the acquisition of particular skills on a regular basis (Ritzema and Sladeczek 2011).

Family: can be seen as a focal point for socialization of children whereby the child initially learns the basic values and norms of the culture they will develop in (DeGregory 2008).

Society: an organised group or groups of inter-reliant communities who generally share a common territory, language, and culture, and who act and interact for collective survival and well-being (DeGregory 2008).

Environment: all that which is outside to the human-host. Can be divided into biological, social, physical, cultural, etc any or all of which can influence the well-being status of populations (Ben-David and Nel 2013).

Cognitive disability: Taderera and Hall (2017) view cognitive/mental disability as a disability referring to children who experience learning barriers without presenting with observable physical disabilities and who struggle with comprehension to a greater level than the average child.

Learning barrier: according to Rorich (2008), a learning barrier describes disability as a neurobiological disorder in one or more of the regions of the brain that enable people to understand spoken or written language. This brain variation can affect a person's ability to read, write, speak, listen, spell, discuss, organize or process information, or understand mathematical calculations.

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Learner: in this study the term relates to children who are attending school (Human Right Watch 2015).

Emotions / Experience: the study uses these terms interchangeably to refer to everyday conversations and experiences that may include meanings and feelings of both mind and body (Levitt 1996).

1.8 Structure of the thesis

This thesis contains a total of six chapters, each detailing a specific process as follows:

- **Chapter one** provides broad perspectives on the topic by introducing and highlighting the background, problem statement, research objectives and questions, and the outline of thesis chapters.
- **Chapter two** evaluates literature sources relevant to this research study, delineating concepts and case studies relevant to the topic. The chapter further reveals the identified gaps in the literature.
- **Chapter three** discusses the theoretical framework. The chapter explains the two key theories that have heavily influenced the development of the research topic, problem statement, the systematic search for literature, the research objectives and questions.
- **Chapter four** discusses the research methodology employed in the study. It expands the research sample, the importance of ethics in research and how data was obtained and analysed.
- **Chapter five** data analysis and interpretation; the chapter also reveals and presents the generated themes from the findings.
- **Chapter six** presentation and discussion of research findings in themes
- **Chapter seven** offers recommendations and conclusions on the study. The chapter outlines the limitations of the study and deduces a clear conclusion having considered the terminologies and the themes that emerged in the case study.

Chapter 2

Literature Review

2.1 Introduction

Randolph (2009) argued that literature review helps researchers to reap extra understanding of the subject, build and decorate information in a unique research area. Researchers gain from being immersed in the vocabulary of the subject area, grasp the necessary concepts, research and experimental techniques that are used in the field, and develop an appreciation of the phenomenon being studied in the actual world. The aim of this chapter is to review and acknowledge the contribution of other scholars to the subject area. The purpose of a literature review is to gain insight into the existing research and deliberations relevant to a particular research area. The literature review is limited on the contribution of anthropologists in the study of cognitive disabilities and the experiences of parents who are parenting children with a cognitive disability, especially in relation to the inability of their children to cope or progress in a mainstream/formal school.

2.2 The Emergence of Disability Studies in Anthropology

Ginsburg and Rapp (2013: 55) suggested that the anthropological focus on people with any form of mental disability was pioneered by Ruth Benedict (1934) as well as Hank and Hank (1948) and Robert Edgerton (1960). Their writings or studies were concerned with mental retardation. Their ethnographic studies told the experiences of people in the United States and encouraged a more sustained continuation on the subject as they confirmed that people had something to narrate. Their publications drew largely on the emic perspectives, that is, "the world/ experience of the subject" instead of the etic "analysis by the other". Their research contribution is to date regarded as foundational for both its insights and attention to a historical trace of disability as a subject area in anthropology as a discipline and as the study of humankind. Albion (2004) further notes that other scholars took up on Edgerton's pioneering work in studying people who are cognitively impaired. His ethnographic work is believed to have set the platform for Nakamura's engaged research at Bethel House with a community of people with psychiatric disabilities in rural Japan.

Nakamura had portrayed this in both her documentary film and her writing. Other early ethnographies had focused more on the phenomenology of embodied difference in marginalised societies. This expanded the borders of the subject and further shaped the theories and the role of anthropology in disability studies, especially in cultural and medical

anthropology studies which looked at schemas - the explanatory model and constructs that people attached to their various types of disabilities. Further publications emerged around medical interventions or pluralistic interventions that people opted for in response to their disabilities. Albion (2004) asserted that since then, there has been a rise of medical anthropologists who have published on various types of disabilities independently while others have collaborated with psychiatrist. Ethnographies in anthropology have since allowed more studies concerned with the embedment of disability in collective social realities Taderera (2017). Social relationships have been looked at as more than just individual tragedy but families and communities are also understood to live the burden of disability. The following section discusses the cognitive disability by various scholars who have indicated that this is a reality that parents in question are faced with, and its broader impact on the lives of both children and their parents as revealed from the literature.

2.2.1 Discussing cognitive learning in a broader context

Taderera and Hall (2017) asserted that cognitive learning barrier is a disability referring in children who experience learning challenges without presenting with obvious physical disabilities and who struggle with comprehension to a greater extent than the average child. Cognitive disability (CD) is also a learning disability caused by genetic and/or neurobiological factors that alter the brain functioning of school going children and those who have completed their schooling journey. Cognitive disability is a type of disability involving various types of cognitive challenges. A person or a child that has experienced a cognitive disability presents with processing problems that can interfere with learning basic skills such as reading, writing and/or maths. These symptoms also come with an inability to demonstrate higher level skills such as organization, time planning, abstract reasoning, long or short memory and attention (Willingham-Storr 2014).

It is important to realize that learning disabilities can affect an individuals' life beyond schooling. They can impact relationships with family, friends and in the workplace. Over the years, the education sector has had an experience with having learners who struggled to grasp and apply their grade instructions or information, which gave rise to the diagnosis of school going children as or suspicion of cognitive learning disability. Cognitive disability is a condition that does not choose race or geographical location but is a human experience. Thus, there have been calls from scholars such as (Pierangelo and Giulian (2008) and (Frederickson et al 2004) internationally, to institutionalize inclusive learning as it is believed that each learner is competent in his or her abilities. The National Council for Special Education report

(2014) states that learners with cognitive learning disabilities are also known as children with special needs and, therefore, should be included in the mainstream education sector.

Studies conducted by psychologists and psychiatrist have confirmed that parents barely accept this learning challenge because they may not be evident to them. Some parents saw symptoms from the early stages of their children's development. Other parents find it difficult to accept their children's cognitive disabilities because they probably did not experience it with their other children. However, psychologists admit that parents are not to be blamed because there is no bluebook for parenting, there is no perfect parent, and parents are heterogeneous by nature.

Pierangelo and Giuliani (2008) noted that parents desire to learn about the progress of their children not only at home but in their place of learning as well and would go on to their schools to question this. Although they would not find satisfying answers as teachers would speak their self-observation because learners with a cognitive learning difficulty proved to be a different case altogether. Their learning difficulties vary as per each individual in a learning space and the required specialised attention is spoken in different modes as their parents and teachers pre-empted their cases, as the scholars argued.

Pierangelo and Giulian (2008) found that children with learning challenges symbolically tread and acclimatize with various difficulties as compared to those with normal identity in an ordinary learning setting. Some problems experienced would include reading and comprehension pressures and spoken or written expression challenges. They also revealed that any learning challenge that is cognitive and behavioural can be moderate, severe or slightly moderate. Depending on their grade, learners differ mostly in their coping skills (Pierangelo and Giulian 2008). As found by Bowe (2005) in a study that aimed to identify differences in learning styles among children with cognitive learning disabilities, some learners were found to be able to adjust to the cognitive learning struggles very well, to a point of getting promoted regardless of the fact that the challenge is still in existence while others are found to be struggling throughout their learning process to a point of having their learning journey being cut short or excluded where there are no means to do otherwise (Bowe 2005).

Even with these differences, a cognitive disability is an in-born problem which is carried on throughout one's lifetime. The problem that prompted the present study, as discussed in Chapter One, is that there are school-going learners that have cognitive learning disabilities

and most of them have not been progressing to other grades. Some parents take such children out of school when they realise that they are not coping, while others keep them until they complete foundation grades and do not make it to high school. Gargiulo (2004), cited in Pierangelo and Giulian (2008), argues that some children are wrongly diagnosed. Where they are correctly diagnosed with a cognitive disability, they are often thought of or misunderstood as 'dumb' or 'lazy' and parents are always advised to look for special schools that will accommodate their children's learning needs. This is the reason why most studies argued against their enrolment in ordinary schools scholars believed that they typically have slight-average or above-average intelligence which educators who do not have training and skills in the area of education are not able to observe. Their brains process information differently especially when compared with other learners who may be having other learning difficulties that are not as obvious as cognitive learning challenges.

In a study that sought the perspectives of parents on mainstream and special school partnership, (Frederickson et al 2004) found that some parents found the absence of special schools in their community to be compromising the essence of inclusion and of inclusive education. Moreover, it is a violation of human rights which mandates education of all children of school-going age regardless of their learning conditions. Hence, I empirically conducted a qualitative study which focused on exploring the experiences of parents of cognitively challenged learners who attended mainstream schools at uMkhambathini. The objectives and theoretical lenses briefly discussed in Chapter One put parents at the centre of data collection and shaped the literature that has been reviewed in this chapter. In a study undertaken by Kavale and Forness (1996), nearly 75% of children with learning barriers lacked socialising skills and experienced rejection from their peers, isolation within the school setting and were perceived by their peers as overly dependent on their teachers. Such learners were not involved much in leadership activities or in self- and group- conflict resolution. This was mostly because of their condition-influenced behaviours which presented cluster of unpredictable emotions as a result of their individual disabilities such as inability to initiate conversations, contain their frustrations and other erratic behaviours as the study concluded. Parents would be evidently disheartened when they had to find out about such news.

On the other hand, Taderera (2015) asserted that managing such unpredictable characteristic of learning challenges could lead to wholesome improvement in the social awareness and academic performances of children living with cognitive disabilities; although the scholar

acknowledged that this would depend on available resources and where the learning challenge mostly lies in an individual case. This would require a close collaboration between the school and the parents. Parents are in a position to know how they shape their children's self-esteem, initiate supporting activities and motivation towards the achievement of their submission to learning. Mumbuna (2010) cited in Taderera (2015) further state that schooling strategies should be collaborated with those of parenting in the case of learning disability.

Exploring the lives of parents was quite important and simple because they exist as the immediate support of their children who may often be concerned or not be aware of whom they are. Parents face exclusion and stigmatization in their families, society and at school for being parents of children with disability. The family, schools and society are the key institutions and being key institutions that may shape or break ones social identity (Thwala et al 2015). Collecting parenting experiences using anthropological research methods would allow other reseachers to know what parents go through while they learn about the daily challenges that are experienced by these children.

2.2.2 The international experience of parenting children with a cognitive disability

o *Daily parenting anxiety*

Parenting a child with any form of disability is a task that is not easy for any parent on any day (Thwala et al 2015). However, the parents of children living with cognitive disabilities remain in admiration and live by the desire to see their children acquire some skills and attain some educational achievements. Baker and Fenning (2007) cited in Thwala et al (2015) reckoned that regardless of the learning challenge, families want to see their children coming closer to the attainment of their full potential, being well received by their communities and being allowed fully-deserved social participation. Taderera's (2015) research findings when the scholar assessed the stresses of parents of children with cognitive learning challenges, it was showed that parenting children with disabilities (CLD) demand parents to have a high level of knowledge and resources to be used in assisting their children. It also requires having access to information that can guide their parenting journey and services that could offer professional support. Kang, Choi and Jin Ju (2016) revealed in their qualitative study that parents who are rearing children with a cognitive disability are trapped in a parenting dilemma and they constantly ask themselves the following questions.

o Where will the child go for any form of educational empowerment?
o How will the child be accepted and cope while attending school?

o How will they protect their identity or how will they prepare him or her to accept their identity?

Fernandez-Alcantara's (2017) study found that families felt sorrowful for themselves and felt that they were not sufficiently doing their parenting duties when confronted with the need to assist their children with tasks such as homework. They felt frustrated by their helplessness especially when they did not know how to assist their children. Taderera and Hall (2017) further held that when parents learn that their child has a cognitive learning disability, they begin a journey that takes them into a life that is often filled with strong emotions and difficult choices. Bingham (2017), in study in Cape Town, found that female parents constantly blamed themselves for delivering children with disability especially because such children will not be socially, culturally and religiously accepted within their immediate families, extended families and the community/society at large.

In Bingham's (2017) study, parents narrated being stressed and exhausted as they had to think about what to do or say to protect their own identity as well as that of their children who are not competent to be in formal schools. Parents explained that they were constantly reminded of their reality by questions such as what grade is daughter/son? Or dictating statements such as *had he/she continued in that school or he/she would be doing the same grade as my son who is doing well in mathematics*. Bingham (2017) further noted that parents mentioned that they carried an unresolved anxiety, were burned out, lonely, unappreciated and uncared for by their families. Additionally, these parents were angry, frustrated, worried, anxious and fearful, shamed, embarrassed, stigmatised and marginalized in their communities which also hinder the social acceptance of their children.

In their study, Skinner et al (2007) discovered that the primary or internal concern for most families in anticipation of the social development of their child with a cognitive disability was that he or she would be without an academic skill or career. They further reveal that whilst parents have such concerns, the pressure mounts as their children would soon need to be exposed to the ecology which would include not only the local community but its resources, way of life and its shared beliefs about disability and development. Parents are often referenced as punished by God and they are mostly not supported by religious organizations, government and non-government agencies. Such pressures have resulted in abandonment of children from birth as children were left at riverbanks in Ghana with the hope of being taken or being killed by river floods.

Parents with disabled children are mostly not supported by the government especially in making sure that every rural community has a special school, which children with any form of disability can access and progressively develop. Taderera and Hall (2017: 1) indicated in their study that "challenges faced by parents of children with a cognitive learning disability are exacerbated by factors such as community attitudes, cultural beliefs as well as institutional challenges. Because of the superstition that evil spirits, witchcraft or a mother's improper relationships cause learning disabilities, women are often abandoned by their husbands to have to bear the burden of caring for the child alone". Haihambo and Lightfoot (2010) also narrated a worst-case scenario whereby in some ethnic groups in Africa, children were neglected by their fathers in cases where it was learned that the children presented with some abnormalities after birth.

2.2.3 Lack of family and other institutional support

Kang, Choi and Jin Ju (2016: 2) observed that "the birth of a disabled child is said to provoke dispute and self-blame within the family and society because parents may be stressed and be faced with a responsibility to act in support of the born child. Parents encounter various demands and restrictions which can cause the family unity to collapse. Parents suffer from endless sorrow, a sense of loss and hope, depression and guilt for their children". Hassal et al (2005: 405) asserted that "many studies have demonstrated that parents of children with any form of disability are likely to experience significantly higher levels of parenting stress than parents of non-disabled children". Oti-Boadi (2017), argued that "raising a child with any type of disability has tremendous psychological problems, often turning into depression, anxiety, and somatic symptoms for parents." Parents of children with disabilities try more and devote more free time to solve their child's problems. It is expected that parents will try, for personal and financial changes, to adapt to new roles to meet the child's unique needs.

Siddiqua and Janus (2017) added that parents are often worried about the transition from pre-school to higher education levels because children living with cognitive learning challenges need specialised school systems which are often not available in rural areas. Bingham (2017: 12) argued that "in South Africa many children with disabilities experience exclusion from health and education services, amongst other support infrastructure, which are crucial for their development". Mubarak et al (2014) conducted a qualitative study about the stresses of parents of children with cognitive disability. Although the study was interested in parents of male learners living with cognitive disabilities and did not account for lack of progression, it indicated that parents' reaction to the birth of a child with an intellectual disability comes

with a combination of emotions which include hopelessness, resentment and loss. Single parenting, as result of the absence of fathers, was recorded as lack of an immediate support that mothers lack and would have appreciated or even gained parenting support. The findings also revealed that the presence of fathers' support in the parenting journey of children with a cognitive learning barrier would have weakened the stigma that they constantly experience in their families and at school.

2.2.4 Parenting Experiences around daily homework (schooling support)

The existing literature demonstrated that different scholars across the globe have prioritized the effects of rearing a disabled child in the family as a focus of their investigations. Kang, Choi and Jin Ju (2016) note that most researchers have attempted to understand the parenting experience and mostly live of mothers who are raising children with a cognitive disability. Their research focused on the schooling support experience that parents encounter when helping their children with homework. A method of data collection included reading parenting diaries which were deemed personal documents that parents have used to unleash their parenting experiences in detail. Oti-Boadi (2017) stated that parents have fears about their children's educational progress, exclusion, stigma, isolation and shame, at home and in schools. According to Moen et al (2011), qualitative studies have indicated that the parenting process is demanding because cognitive disability demands parents to provide daily homework/academic support to their children whose learning abilities are challenged. The findings from (Moen et al 2011) also revealed that parents were not coping in assisting their children in doing homework.

The publication that sought to assess the coping strategies of parents, (Moen et al 2011) it was revealed that most parents narrated that they are troubled every time they attempt to help their children to do their homework because the children are not able to retain the information like other children. They find themselves having to repeat one and the same thing over and over again and that got them frustrated. It is difficult for such parents to accept that their children are not coping even at school. Parents narrated that the schooling support remains a 'constant battle', from doing homework to making changes to their daily routine, and that this is a non-ending parenting cycle. They further narrated that they tend to become more punitive to their children which cause the children to become more anxious and begin to hate school completely.

2.3 Unpacking the call for the "inclusive education" of school-going learners with varying abilities/disabilities

The position paper of the United Nations Children's Fund (2012) advocates for the right of children with disabilities to education, as well as an approach to inclusive education based on human rights. The report contains the slogan "Education for All" (EFA), which is an international commitment to ensure that every child and every adult receives a good quality basic education based both on human rights and on the generally accepted belief that education is the basis of individual well-being and national development. In the position paper, inclusive education systems are those that have developed schools which are based upon "a child-centred pedagogy capable of successfully educating all children, including those who have serious disadvantages and learning disabilities. The merit of school is not only that they are capable of providing quality education to all children; their establishment is a crucial step in helping to change discriminatory attitudes, in creating welcoming communities and developing an inclusive society.

UNICEF's (2017) position paper calls for a radical change within the school system and argued that if the values and principles of teachers are incorporated, the world's most vulnerable and deprived children will realise their fully deserving right to education. This on-going goal of the UNICEF has a holistic approach of dedication and incorporating the values involved in the process of education. The envisioned goals as listed by the UNICEF (2012) to help promote education of children with disability included, giving equal value to every being; Helping everyone to experience their own existence; Promote learning and participation in education; Elimination of exclusion, discrimination and barriers to education and participation; Develop cultures, policies and practices to promote equality and equality for all; Learning comprehensive ways to share comprehensive lessons; realising the difference between children and adults in the forms or modes of learning. Recognize the right of children to a high-quality education locally; Improving staff and parents as well as children's schools and emphasizing the value of building positive school communities.

Within the proactive action that was taken by UNICEF (2012) is the unpacking of the case of inclusion that stresses the statement of human rights, a name for strong social and instructional benefits. The inclusive approach can change attitudes toward diversity in schools by educating all young people together, leading to increased social cohesion where: school-children with disabilities are much less stigmatized and more socially included; learners without disabilities could learn tolerance, acceptance of differences and respect for

diversity; children with disabilities have access to reputable progressions available in special schools. This will result in higher achievements for children than in segregated environments. Indeed, through radical changes in the way school education is planned, implemented and evaluated, the provision of inclusive education could have innate benefits for children. Education is a tool to ensure that people can enjoy and defend their rights in society and contribute to the process of democratization and personalization in both society and education (UNICEF 2012).

McKenzie and Kahunde (2012) observe that the provision of education for people with disabilities has been part of a democratic transformation that has recognized South Africa's education system as promoting access to education for all. The Constitution of the Republic of South Africa (Act No. 10, 1979, Section 29 [Bill of Rights]) provides that everyone has the right to basic education, including elementary education and further education. A framework for a comprehensive system of education is laid out in White Paper 6: Special Needs Education: Building and Comprehensive Education and Training System. The scope of this policy is wide as it seeks to meet the diverse needs of all learners who face barriers to learning.

This policy calls for important conceptual changes based on the following assumptions: All children, adolescents, and adults may learn with the necessary support. Learning can be incomprehensible if the system is unable to recognize and accommodate the diverse learning needs. The policy states that changes in the concept of providing support to learners facing learning barriers are necessary to achieve inclusive education. South African Law (Law 79-84 of 1996) states that public schools must accept learners and meet their educational needs without undue discrimination. The law provides that where "reasonably possible", states must provide education to children with special needs in mainstream public schools and provide learners with appropriate educational support services.

The Head and Head of Department (HOD) must take into account the rights of parents and the principle of "what is in the best interest of the child". Public schools must take all appropriate measures to ensure that physical facilities are accessible to all students, including those with disabilities. The Act states that special schools must be accessible to neighbouring full-service schools and colleges in light of existing experiences and resources. As mentioned in White Paper 6, it is part of the District Support Service, incrementally, to create special schools which can become resources for other schools within the district.

Werning et al (2016) agree that the admission of special education need learners into formal schools is accepted and widely enacted and celebrated in countries around the world through inclusion. The Declaration of Education for All is traced back to the World Conference on Education for All held in Jomtien 1990, Thailand. Ten years later in Daker, Senegal, the World Education Forum was hosted for the reinforcement of the commitment (2000). The conference discussed six goals of education for all set for 2015 under the leadership of the United Nations Educational, Scientific and Cultural Organization (UNESCO). Werning et al (2016) also indicate that the Salamanca Declaration and Framework for Action on Special Education Needs (Spain, 1994) were the driving force behind most countries in the world to introduce inclusive education in. The conference backed by UNESCO lasted for 3 days. It invited a variety of stakeholders including government officials and policy makers to deliberate the urgency of caring for special education needs (Salamanca 1994). Frankel, et al. (2010) assert that many countries that have attempted to implement these polices have struggled for years to bring the actual realization of inclusive education into practice.

2.3.1 Cracks in the successful implementation of the "inclusive approach"

The realization of policy objectives has been threatened in most parts of the world by the inadequate training of educators, insufficient support from government due to the lack of a political will. Ordinary School Policy and Admission to South African Schools (South African Republic Act of 1996, 84, 1996) allows for the recognition of learner diversity and a Bill of Rights for Quality Education in a single Educational System. These two documents provide the basis and inducement for the ultimate initiative to implement a comprehensive education policy in the country. As referenced by the Ministry of Education (White Paper 6 of 2001), inclusive education revealed its philosophical position within the niche generated by democratic dispersion and implied national independence. Equality and justice, as stated in the Constitution, are defined as an educational system that ensures that every individual has the right to care for, enable and contribute to its citizens in a changing and diverse society.

Engelbrecht et al (2005), note that all these policy prescripts advocate for a schooling environment that does not discriminate against any learner because of learning challenges or barriers. The endorsement of these policy frameworks advances the inclusive approach which was identified as the gap during the apartheid era. They also advocate for the establishment of learning centres that do not discriminate children that may present with symptoms of poor retention or learning/cognitive barriers. Donohue and Bornman, (2014), Mckenzi and

Kahonde (2012) and Mapuranga and Nyakudzuka (2014), in their independent studies, revealed that while there has been attempts in mastering or integrating inclusive learning which considers that learners in the same classroom or school. This would not equally promote competence and certainly, will not prevent researchers from reporting that South Africa's inclusive education policy is still characteristic of both high discrepancy and ambiguity where this remains to be a prevailing issue. Good policies have been poorly coordinated or implemented and they do not seem to be benefiting the schooling environment and seldom appear to benefits children or their parents.

Parents are regularly placed in the position of having to advocate for the inclusion of their children in the appropriate learning curriculum and/or to become beneficiaries of quality education. Research findings revealed that some parents have opted to keep their children out of school, and they struggle to provide them with daily learning activities. Ferguson (2008), Kiuppus (2014), cited in Moljord (2018:3), point out that the application of inclusive education has presented continuing challenges. Frederickson et al (2004) state that most countries have poorly coordinated the successful implementation of policies that promote the inclusiveness of children with a variety of disabilities and that includes those who need to attend special schools because of their cognitive challenges.

Their study observed that parents attempt to put them in mainstream education centres, but these accommodate them only to a certain grade. The study also noted that countries that have tried to implement their inclusive education policies also struggle to find educators that are qualified to teach such children. Sending them to education centres does not advance them as they should be advanced either art or vocational skills over the last decade. Moljord's (2018) study further noted that the problem is not only the poor coordination of policies but there is no clear curriculum that guides educators in both public and special schools.

Findings by Moen et al (2012) revealed that parents are always in fights with educators who do not seem to be accepting their children in mainstream/formal learning schools. Their children are constantly reminded that they will never make it to the next grade without providing the necessary support that they need. It was said that having a learning/cognitive barrier does not mean that one is totally not a capable learner, but the problem is that extra support may be needed by the disabled learner in order to work on the completion of their tasks. Bornman and Rose (2010) observed that it is not teachers who are not willing to

support learners with learning barriers, most South African schools are still without a curriculum that accommodates the variety of learning patterns of different learners.

There is a general lack of support and resources from higher structures and a prevailing negative attitude towards disability which contribute to the general disorientation in South African schools. Mak et al. (2010) conducted a qualitative study in China where 188 Chinese parents with children living with Autism were recruited to participate in study which confirmed that the stigma attached to learners with autism does not only affect the discredited learners but extends to the individuals that are closely related to the stigmatized children. Parents were listed as being the closest to fall on the receiving end where societal misconceptions blame them for giving birth to disabled children.

A study conducted at the University of Western Cape (Joorst, 2010) further recommended schools for all handicapped learners where educational provision will meet special educational needs for all learners in different communities in order to alleviate pressure that parents and children face, through provision of necessary support. Bingham (2017: 14) further stated that "at often times, families and others who care for these children also experience lack of support, as they struggle to care for their children because of limited resources. Most communities do not have specialized schools to cater for their educational needs. This is a policy challenge that government still needs to respond to as it is seen to have been less prioritized or poorly coordinated".

The Human Rights Watch report (2015) observes that South Africa stressed many forms of discriminatory antics and obstacles that children with learning disabilities face in trying to access schooling that care for inclusion. The report highlights several persistent challenges including discrimination in access to education. Children with all types of learning disabilities continue to experience discrimination when they have to access to all types of public schools. The school often decides whether it wants to or can accommodate students with disabilities or special needs. In many cases, children with intellectual disabilities, multiple disabilities and autism or fatal alcohol syndrome are particularly disadvantaged.

Many learners in regular schools face discriminatory physical and behavioural barriers that they must overcome to obtain an education (Human Rights Watch 2015). Many learners in special schools for children with sensory disabilities do not have access to the same subjects as children in elementary schools, jeopardizing their access to the entire curriculum. They are not supported and generally do not have a quality education, which is typical of many public

schools which have poor learning environments. Public schools, mainly in rural communities, continue to suffer momentously from lack of teacher training and awareness of inclusive education methodologies.

In their study on inclusion of learners with disability in mainstream setting (Keogh et al 1997) argued that the inclusiveness of learners living with cognitive disabilities is not only threatened by the poor coordination or the implementation of public policy, but that the policies will always be compromised by a lack of integration of socio-cultural perspectives on learning processes which is an integral element that recognizes and rather understands learning problems in cultural groups. These scholars argued that if cultural backgrounds of learners are understood as part of learning process, there will be a realization that learners are capable but they need to be supported in ways that will accommodate their conditions and ways of socialisation. The study argues that knowledge about learning disabilities and cultural diversity has been limited to individual's inborn characteristics of the body such as a child's neurobiology or the organic base of the problem (Keogh et al 1997).

In another aspect of the same study (Keogh 1997) produced finding from anthropology and social cognitive psychology to argue the importance of a holistic consideration when it comes to problems of learning and learning disability of children in different cultural backgrounds. The study further found that it was nearly impossible to separate a child's learning competencies and problems from the context in which they live and function (Keogh et al 1997). The scholars postulated that a biological organism participating in a cultural reality and children with learning problems will be deeply affected by that cultural reality. Without mentioning it, this study was alluding to a holistic approach when studying continuous development and socialization of people living with disability, which is a gap that my present study has aimed at attending to.

Thwala et al (2015) sought to explore the experiences of parents of children living with cognitive disability. The findings revealed that parents talked about how they were constantly being called by educators who overly emphasised that their children were not coping in the mainstream classes. This increases a parenting burden which could be alleviated by the schooling support. Parents spoke at length about the exclusion of their children as some of do not progress from one grade to the next. The UNICEF (2012) position paper state that children with disabilities of any kind often live outside of mainstream society in residential institutions or at home with family members, with little contact with society or the outside

word. Their situation rarely gets normalised within their communities. They instead experience discrimination and negative attitude from other school learners. These behaviours hinder the process of inclusion. On the other hand, the language used to describe disability perpetuate negative stereotypes and prevent full inclusion.

Professionals, as well as society in general, use derogatory terms such as "defective" and "disordered" when they refer to learners with disabilities going to school, when these "defects" must be corrected instead. The Human Rights Watch research report (2015) pointed out that the capacity of classrooms in public schools is not conducive as it cannot accommodate learners with different learning needs. Teachers in mainstream schools have to teach over 40 children in one classroom, including those with disabilities. In such large classrooms, teachers resort to the classic models of routine learning and teaching at the front which is believed to limit face to face attention and observation of all details of learning process. This is said especially with children with moderate level of needs and support when teachers do not observe the children to assess their pace or level of learning (Human Rights Watch 2015).

The Comprehensive National Strategy on Support Services for Children with Disabilities (2009) states that the South African education system is currently failing to provide adequate access to basic education for people with disabilities. There is insufficient and inappropriate school placement available to special needs learners and the South African constitutional mandate of ensuring access to quality basic education for all children, regardless of geographic area, has failed. The limited number of schools and capacity in rural areas makes it impossible for children with disabilities to move away from their families to receive education. It fails to integrate a significant number of children into society and to contribute productively to the community. This puts a lot of unnecessary burden and financial pressure on parents and society.

2.4 Identified Gaps in the Literature

After immerse analysis of the literature, the general understanding demonstrated that the journey of raising and caring for a child that is living with a cognitive disability as framed within constant changing-routine adaptation if not constant mourning difficulty for parents. The study recommended that government should build rural schools that will fully cater for children with cognitive disability so that they could enjoy their right to learn fully and without compromising their education in the process. The premise of the present study is that

studies of this nature have not been done in rural places like uMkhambathini where there are parents whose children are affected by cognitive disability. Previous literature confirms problems associated with disability but lacks in the recommendation of sensitization of policy, especially in safeguarding the lives of families who find themselves in situations of disability, and in accordance with their life histories. As a result, desired assistance has not been implemented, and possibly overlooked, in the policy recommendation leading to scarcity of special schools.

The lack of literature compelling the establishment or encouraging provision of special schools in this rural community has seen parents considering sending their children to ordinary primary schools despite their condition, but in the name of inclusion. This is a research gap that this study is willing to bridge. The research investigates how parents cope with the situation within their cultural, historical, and socio-political contexts in order to produce attested and situated knowledge. Through consultation with literature, I also find it important to clarifying the ambiguity in terminology and concepts used in this study.

The usage of some concepts and terminologies may not have been consistent. Concepts such as parent, parenting and learning barrier or disability, may be known and feature in our everyday language, but the meanings associated to these concepts in this chapter may vary as postulated in the previous chapter. The study suggested that understanding learning disability and knowing what to do about it requires a conceptual framework that would take into account these core aspects and put out a recommendation which shows that a socio-cultural dimension has implication for defining and studying learning disabilities. This way, possible assessment and intervention effort would be well delineated.

2.5 Conclusion

Literature arguments presented by different scholars and researchers have given an indication that cognitive disability is a part of human condition that is mostly found in school-going children. Experiences of parents have given an indication that parenting a child with cognitive disability symptoms is a journey that comes with a variety of challenges. Parents who are the closest people to their children try different ways to find balance in between daily demands and restrictions that they encounter with their children. The content of this chapter will be used to develop themes which will be used for analysis and interpretation in the data analysis chapter.

Chapter 3

Theoretical Framework

3.1 Introduction

People often believed that nurturing a child was natural and that parents knew what to do about discipline, care and appreciation, among other things. Joseph and John (2008) stated that social change made it difficult for most parents. Bronfenbrenner (1979), cited in Thomas and Stephen (2007), states that the effects of parent-child relationships are intertwined with other effects in the broader social context. The separate and equally persuasive challenge to direct causal assertion between the quality of outcomes between parents and children are the multiple layers of the environment and the interrelationships and processes of parent-child identity formation.

3.2 The choice of theories and complexity of interactions

This study employed ecological and identity theories. These two key theories heavily influenced systematic search for literature sources. Based on the evidence in literature, disability is not anchored in the body, but created by social and structural conditions that prevent the uncontrolled participation of many souls and bodies (Ginsberg and Rapp 2013). The key theories have revealed and detailed perspectives and other factors to consider regarding the embodiment of disability in social living. Therefore, this study valued and employed life history methodologies in order to demonstrate admissible evidence of interactions. This will be discussed in the following chapter. This chapter reveals how the theoretical framework had strengthened the rationale and provided context for the present research problem. In this study I reviewed both anthropological theories and the literature concerned with the embedding of learning disability within a holistic socio-cultural setting as presented in the previous chapter.

Parenting is embedded in a myriad of social factors that affect parental-child development. These range from immediate and extended families, environmental violence or environmental factors such as familial poverty and the environmental niche in which children live, that is, a mixture of environmental experiences and micro-environmental risks (Super End Harky, 1986, cited in Thomas and Stephen, 2007). Bell and Harper (1977) cited in Thomas and Stephen (2007) summarized several studies on different types of parenting, showing the ways in which parents characterised their experiences of caring for children who are living with

cognitive disabilities. The main characteristics of children where based on gender, age, temperament and physical or intellectual or behavioural disabilities.

3.3 Defining theoretical framework

Du-plooy et al (2014) define theoretical framework as a concrete set of thoughts and theories related to the phenomenon studied. It serves an important role of outlining the theoretical scope while assist a researcher to develop and examine a research topic, problem and questions. This study utilized ecological theory and identity theory as its principal theoretical frameworks. The two theories converge in this anthropological study in that both theories provide an understanding that both societal components and social interaction do not happen in isolation but in an inclusive manner. The theories find relevance in this anthropological study because the study of anthropology is concerned with exploring and understanding humankind, which is inclusive of people's living and their interaction with their environment, in order to understand them better and recommend responsive policy for change. This study has consulted various and relevant literatures; together with relevant theoretical framework which has helped in collecting and in the analysis of findings.

This study focused on the endured experiences of families of children with a cognitive learning challenge (CLD). I utilize the phenomenological approach as a method to select theories that uncover the convergence of disability as an identity and socialization or an issue with socialization. Over the last century, phenomenology has evolved as a philosophical perspective to illuminate previously ignored phenomena related to the human experience (Woznar and Swanson, 2007). Phenomenal reality in anthropology is better understood through tangible or lived experience, since only those with the relevant experience can communicate it to the outside world. Furthermore, phenomenology ensures the reliability of findings through the use of parenthesis. Bracketing ensures that researchers do not allow their assumptions to shape the data or impose their understanding on the data. It suggests that researchers must set aside their own views about the phenomenon in the process.

3.3.1 Ecological theory

Ecological theory originates from Urie Bronfenbrenner who studied the dependency between man and environment in the late 1970s (Harkonen, 2007). Through studying ideas associated with definitions of ecology and socialization, Bronfenbrenner observed how an individual grows to become a fully-fledged member of society. In this study the theory suggests that socialization occurs in contexts and the child is placed in the centre of concentric circles as

modeled by Bronfenbrenner (1979). The ecological theory finds fit in this study because it allows the researcher to record how people live and be able to collect experience that tell how a person has been included or discriminated against by virtue of being different in a particular environment. The theory explains the phenomenon of human development and is inclusive of how people are daily socialized where they live (Harkonen 2007). The holistic approach within this theory is that it considers human development as influenced by different types of environmental interactions which have been considered in the wording of research objectives and questions. The critical contribution of this theory is that it acknowledges that the environment influences human behavior and how people interact with each other; as this was demonstrated the analysis and interpretation in the following chapter five (Recklein 2013).

3.3.2 Theoretical Lenses of the Ecological Theory

According to the theoretical perspective, there are four stages of development that are associated with the development of an individual, namely, the micro, meso, exo and macro-systems. These systems are said to affect and shape the identity as well as experiences of people, which in this case will be the life experiences of parents of children with cognitive disability. For instance,

- The micro-system entails a child's biological nature and direct interaction with their immediate environment which may include psychological, social and emotional support, family and institutional involvement or participation.

- The meso-system connects processes that occur in multiple microsystems and it points out that school and families are the principal microsystems interacting with early life and organized out-of-school activities. It argues that coordination of activities across all settings is fundamental for better development.

- The exo-system communicates micro-systems where individuals are involved but not directly embedded. At this stage influences from other people involved in one's life is discussed such as parents' encouragement of participation of their children in activities they have entrusted them for development.

- The macro-system represents the outermost system considered a set of key beliefs, values and norms that are reflected in the cultural, religious and socio-economic organization of society. This phase is believed to impact further development within

all other systems and acts as a filter for individuals to interpret future experiences (Ettekal and Mahoney 2017).

The macro-system is one key lens of the ecological theory that gives insights on individual development and societal participation. It predicts why people within one society have different experiences and opportunities in the same activity. The macro-system draws from influences of social class and culture to make such predictions. The theory looks at social class as an individual's or family's economic and educational position occupied within a larger hierarchical community while defining culture as the system of values, practices and beliefs of a particular ethnic group (Ettekal and Mahoney 2017). The theory holds that such areas of macro-system should be given a more in-depth exploration. It also holds that questions, such as how activities should be personalized for targeted populations such as youth with disability from marginalised communities, should be addressed. Furthermore, the theory contributes massively to this study in that it seeks to promote a healthy development and positive social interaction as these features are said to bring about essential children's sense of belonging while creating a safe environment regardless of social status or identity.

3.3.3 Ecological View of Socialisation

The theory simultaneously considers socialisation a way of becoming a member of a society and understanding the phenomenon of education and the problems associated with it (Harkonen 2007). It considers out-of-school activities to be part of childhood ecology which help elucidate the peculiar features of activity settings that promote positive, healthy growth, and how relationships between activities and other settings contribute to the development process. The theory argues that these levels are related to smaller, proximal settings, in which individuals interact directly with larger, more remote settings that affect contingency development. Ecological theory scholars interested in the meso-system are the criteria for programs that conform to parental values or school mission statements? This research can be extended by asking such questions or engaging in activities outside of school that are influenced by school experiences or family responsibilities. This way, human life is well developed and changed.

For Ettekal and Mahoney (2017), the contextual knowledge of ecological theory and the consideration of all its important developmental stages, the experience of parents of children with cognitive barriers in learning is a pervasive and persistent problem. Considering the details of the theory may play a role in helping professionals better understand the unique

struggles and needs of these parents. The knowledge of this theory will help to set aside interventions for when similar situations occur in the country or in the same situation in the future of other parents in need for such interventions (Ginsburg and Rapp 2013). This helps normalize their own experiences and emotions, and in some cases can direct them to resolution. For professionals, this study can provide results that will help determine treatment and support plans when dealing with such experiences.

- *Anthropological Lens and the Use of Ecological Theory in this Study*

Anthropologists seek to use the ecological theory as a platform to live up to the principle of holism. This is a life support principle for the consideration of all aspects that affect human life when doing and documenting any anthropological (Recklein 2013). The theory was adopted and used in this study as the topic sought the understanding of experiences of parents in their changing environments, as it was evident in their narratives that any change from one environment to the other, meant for new adaptation and new socialization. In addition, the problems that impact the lives of parent and together with their children were mainly due to the lack of holistic consideration of their personal beings as parents of children living with cognitive disabilities.

The study sought such grounded theory in order to explore the lived experiences of parents in the context of parenting children that are living with cognitive disabilities (Kasnitz and Shuttleworth 2004). The theory allowed this anthropological study to learn about the depth and lead to social processes of being such parent from home environment to larger interaction with broader communities. The theory found most relevance in this anthropological study in that it entailed and provided that every new stage of the ecological theory from micro, meso, exo and macro-systems was a new lens of culture in that parents and their children were forced to blend in with their new multi distinctive population from their home environment, adapt and live by the new governing norms of the particular environment.

3.4 Identity Theory

Burke and States (2009) define identity theory as a social psychological theory that seeks to understand identities, their sources of interaction and society, their processes of operation and their consequences for interaction and society. The theory holds that all people derive their roles in society and the specific identities, as well as their individual characteristics of how humans can be perceived as able/normal or disabled. The theory is consistent with the point of view of ecological theory because one's identity and experiences are shaped by the

environment and the process of socialization and humiliation. Furthermore, Golubovic (2010) agrees that an anthropological approach to the concept of identity is essential to understand that one's identity is a condition that could determine their inclusion or exclusion; hence this theory finds relevance in this particular study. This theory allows us to understand that people are born with a certain identity, that they also live in cultural conditions such as "second nature of man", which then allows them to be conceptualized or understood differently from others. Therefore, this study focuses on learning about the life experiences of parents of children with cognitive learning barriers. The perspectives of identity theory allowed the study to inductively understand how micro, meso, exo and microsystems as stages of progressive social life can create and influence identities and the experience associated with it.

At the same time, Battles (2011) argues that identity theory can help humanist orthodox conservatives who associate disability with marginalization and poverty and see it as the result of inevitable human experience. Anthropologists can refute such beliefs and help alter the association of the social statuses of parents who have children with disability with inequality, dependency by lobbying for the acceptance of identity regardless of physical condition (Battles 2011). Furthermore, the scholar suggested that the political struggle for disability rights is central to the attempt to portray disability as a socio-historical construct, which researchers should consider.

3.4.1 The View of Socialisation in Accordance with Identity Theory

Battles (2011) went on to define identity as a set of meanings that define who one is when one is an occupier of a particular role within a particular community, a member of a particular group, or claims particular characteristics that identify him or her as a unique person. Identity theory designates causes and consequences of identifying with a particular role. The content of this study suggested that parents are more likely to live the identity of their children themselves as custodians, while fulfilling the role and responsibility of educating children with cognitive impairment in society (Oti-Boadi 2017). This theory is important for this study because it allows for the study of the daily experience of parents affected by the issue of disability. Applying identity theory in their study, Hassall et al, (2005) showed that parents of children with cognitive disability lived with the consequence of higher level of parenting than communal parents of normal children.

An inductive sentiment that was shared by various sources on this issue is the identification of parents as the primary care providers for their children. The literature has established that giving birth to a child with any disability has its meaning in society. As scholars such as Skinner et al (2007) and Taderara and Hall (2017) observed that parents are socially impersonalised by giving birth and caring for a child with learning disabilities. It is understood that such symbolic reference to society is the beginning of a journey of demands associated with the role of their primary caregiving.

- *Anthropological Lens and the Use of Identity Theory in this Study*

In an anthropological lens, the concept of identity is viewed as culturally constructed (Golubovic 2010). As a discipline that is holistically concerned about humankind and their continuous socialisation, anthropology takes significant interest in learning about the impacts on human culture both positively and negatively. Disability has presented itself as both an identity and a condition that impacts human individual in their personal capacity and in their collective socialisation as communities. This was evident in an ethnographical study that was presented by (Kasnitz and Shuttleworth 2004) who noted huge exclusion as a result of perceived bodily differences. The two scholars also regarded disability as a stigmatized identity that its path crosses to even affect families of a person that is perceived as a disabled person. Their lives are then forced into peripheral and society-defined value of life, although in one single environment. The parents have to cope with the proliferated insults which endanger their self-image, social life, and even economic opportunities. With the above assertion, this study then reiterated that to do anthropology, the hallmark idea is to do ethnography in order to learn in-depth about human experiences in their socialisation; and before dealing with situations. Anthropologist, in their personal interaction with their subjects, they are able to learn that culture and human body are not fixed in what is thought to be normal but these are as dynamic as they are subjected to any change (Oti-Boadi 2017). In this regard, an anthropological documentation of identity as part of culture and as a condition that is not inevitable to redirect human socialisation is imperatively important as reference for cure and restoration of the disabled people as prominent members of human culture to as nearly a normal existence as possible (Kasnitz and Shuttleworth 2004).

3.4.2 The Enactment of Theories in Anthropological Studies

The two theories that were chosen in undertaking this study were consistent with aspects of cultural anthropology. Cultural Anthropology introduces studies of human culture, beliefs,

practices, values, ideas, technology, economics, and other areas of social and cognitive organization (Blount 2011). This field is based primarily on cultural understanding of populations of living humans gained through first-hand experience or participant observation. The two theories are grounded in the field of cultural anthropology and have contributed immensely in the overall research study. Ecological theory and Identity theory informed the wording of research objectives, questions and the systematic search for relevant literature for the study. These theories were also influential in deciding the research design, methods of data collection and how the data is presented, analysed and interpreted.

3.5 Conclusion

The two theories, ecological and identity theory that are used in the study informed the the selection of appropriate methodology, conceptual, and theoretical perspectives to be considered in the study. In conducting literature review and data that collection, I offered justification and rationale for the choices made and developed the context of this study through a review several relevant source. This was done for a purpose of scrutinising the extent to which the concepts, theories, and methods of socio-cultural anthropology have been applied to the conceptualization and understanding of the socialisation of people living with disability. The literature review and research findings were motivated by the theoretical frameworks explained above. Provisions of the theoretical framework were mostly used to analyse and interpret data as presented in chapter five.

Chapter 4

Research Methodology

4.1 Introduction

Research studies are conducted to explain and comprehend the nature of a phenomenon. All good studies are based on some underlying philosophical assumptions and show which research methods are suitable for developing research expertise. The research methodology chapter is one of the most integral chapters in any anthropological research. It allows the researcher to take the reader through a detailed account of the study techniques and for the anthropologist to document experiences that were encountered in the course of collection of experiences.

Research method is the science of the thesis in my own understanding. It is a mirror that confirms that the researcher did embark on a research that was ethically cleared. Pauline (2009) states that research implies a search and re-search or a re-examination of the existing situation of humans (this study was conducted on parents who have accumulated experiences as a result of rearing children with cognitive disability, also known as a learning barrier). These parents would have not had this experience if disability were not part of a human condition. Furthermore, Pauline (2008) asserts that a scientific research could be defined as an organised and systematic enquiry into a phenomenon to discover new or verify existing knowledge. Anthropological research is undertaken to know something, to tell an experience or a story about lived experiences. Akhtar (2016) stated that a scientific research should have a research design which is the structure of the research. It is also the "glue" that holds all the elements in a research project together; it is a plan for the research work.

4.2 Research design and paradigm

The research paradigm within which this study was underwritten directed to the adoption of a qualitative research methodology for the gathering of knowledge. This was due to a series and depth of subjective experiences that the study uncovered in the experiences of parents. . While theories suggest many perspectives to be taken into account when studying parents on the journey of caring for and raising children in the context of education, the literature confirms that parenting experiences are broad and remain subtle. They discover aspects of their social environment that they find themselves in. This study adopted a qualitative research design to enable flexible and reflective research enterprises. A paradigm as discussed by Creswell (2012) in social science research is viewed as a set of core beliefs. It

represents the world view, for those who hold it, the 'form of the world', the position of the individual within it, and the possible scope of interaction with that world and its parts.

The qualitative research approach illustrated that the researcher's philosophical focus was reflected in this study, which examined the living experiences of parents of children with cognitive learning barriers who are excluded from rural formal education. This pattern has a significant impact on every decision made in the research process, including decisions about methods. It is argued that important knowledge can be gained by examining the subjective experiences of parents with learning disabilities, where the educational future of their children has become uncertain (Anis and Chen 2012). Bryman (2016) argued that the importance of qualitative approach is that it enables a researcher to accommodate interpretation of different meanings prior to conducting a study in the field.

This research was conducted within the interpretivist paradigm which asserted that researchers have to study and describe significant social action in the social sciences beyond mere assessment of social issues. According to Creswell (2012), a paradigm may be defined as the primary mannequin or body of reference used to shape the observations and reasoning of men and women or groups as set out in the previous paragraphs. When considering social reality studies, qualitative analysis subscribes to the look-up model of interpretivism. Interpretivist researches have an assumption that highlights the large differences between people and objects, emphasizing that the two cannot be studied in the same way (Du-Plooy 2014).

Du-Plooy (2014) further explained that what made up this important variation is that it indicates that humans change all the time, and, unlike objects, they are destined to change all the time, driven by their environment. Anthropology in the cultural field recognizes that human biology or identity varies and socialisation is a result of this variation; also, socialisation changes through variation (Kumar 2015). This study sought to explore the experiences of parents of children with cognitive disabilities. These emotional states were perceived as a result of a disability, that is, a condition that affected humans in their broader social reality. The research topic required that the event be studied in the field where it occurs as is typical of anthropological studies. It must also seek the designation of affected people to the centre of the affected community to obtain well-informed responses (Lune and Berg 2017).

4.3 Justification for using qualitative research in the study

This study employed qualitative research methods rather than quantitative or triangulated research. As a Principal Investigator, my interest was to humanely study the lived experiences of parents of children living with learning disabilities with the intention of learning from their experiences. Kielmann et al (2012) argue that quality research is humane because it focuses on the personal, subjective and empirical basis of knowledge and action. It is comprehensive because it seeks to establish the meaning of a particular behaviour and the way in which such an issue is handled in a context. Qualitative research refers to a tradition of research that has more to do with meaning and interpretation (Lune and Berg 2017).

Strauss and Corbin (2008) and Levitt et al (2017), quoted in Mahajan (2018), says that qualitative research is inductive in nature and researchers usually review definitions and observations on a particular issue. Punch (2013), quoted in Mahajan (2017), states that it is a form of social science research in which non-numerical records are collected and processed to collect and analyse people's experiences and for working with non-numerical data that allows us to attain a deep perception of social life with the aid of reading targeted populations or places. Walia (2015), cited in Mohajan (2018), agreed that qualitative research focuses on phrases instead of numbers. This type of research looks at the world in its environment and interprets the situation to understand the importance of people's daily lives.

Qualitative researchers are fascinated with people's beliefs, everyday experiences and meanings from people's perspectives attached to such experiences. They accumulate emic views and pay attention to the rationalization that is part of the experience. It is what anthropologists view as having an insider or emic viewpoint. Qualitative researchers examine the local knowledge and seek an understanding of a particular program, individuals' experiences, meanings and relationships, social processes, and related factors that bring a group of people to the margins.

Qualitative researchers are always trying to understand what they see and hear in a context. Their approach to understanding what is happening is interpretive. So, the goal of a qualitative researcher is to explain the depth of experiences rather than merely describing. Qualitative research methods are generally open-ended and in-depth while assuming a naturalistic approach. In other words, this research, as shown in Chapter 1 of this thesis, aimed to study objects, people, and events in a natural (non-experimental) setting. Thus, this study is about parents residing at uMkhambathini Community (being their natural setting) as

discussed in Chapter One of this thesis. This study uses a qualitative approach and provides synopsis and contextual information through an analysis of diverse but directly narrated cognitions on the subject of the study (Ormston et al 2014).

Ormston et al (2014) argue that qualitative research is used to assess the subjective experience of human lifestyle in the context of the social environment. Qualitative strategies include techniques that provide a subjective assessment of an individual and emphasize the importance of providing data on social experience. The collected data provides a simple test of social interactions and methods. The researcher positions humans at the coronary heart of the research agenda in an identical way as the qualitative method (Hartley and Maht 2013). Astalin (2013) states that qualitative research is a systematic scientific inquiry which seeks to build a holistic, largely narrative, description to inform the researchers understanding of a phenomenon.

- *Conditions in which Scholars use Qualitative Research Design*

According to (Thompson 2013) qualitative research could be understood as anything else, and that which cannot be reduced to numbers, or else if done so; it cannot provide full harness of depth and significance in numerical terms. Thompson (2013) then provided that sought for quality of information should be given as precondition for any research interest to use qualitative research design. Daniel (2016) also extended similar sentiment in agreement with (Thompson 2013) that a determining factor for any topic that would seek the use of qualitative research design, it must be on the basis of discovering truth which involves the combination of reasoning and experiences. Qualitative also equips researchers with methods to employ in data collecting their data to give full description of the research with respect to the participants involved, such methods would involve on field research through participant observation and focused group interaction to allow or create wider understanding of behaviour and the phenomenon that is being researched (Daniel 2016). The original topic was conducted in anthropology and its natural essence is social science as it seeks quality of data in details of experiences of parents. Thompson (2013) provided that quality may be looked at as expression of data that cannot be immediately translated to numeric but it fits the collection of data such as experiences or the views of parents regarding socialisation of their children who are living with cognitive disability in mainstream schools. Also, in studies that are concerned with why question, where researchers want to provoke multitude of reasoning

from their subjects. This meant for the engagement of specific ethnographic methods for the collection and analysis of data.

4.3.1 Characteristics of Qualitative Research

One of the most basic features of a qualitative study is that it does not involve statistical or experimental calculations. Denzin (2002 1998), Chalhaub-Devile (2008), and Lazarton and Taylor (2007), quoted by Rahman (2016), say that qualitative research provides a detailed description of participants' feelings, opinions, and experiences and interpret the meaning of their actions. Qualitative research is used to better understand issues related to the development, administration, and interpretation of people's descriptions. Qualitative researchers explore participants' inner experiences and find out how values are formed in and through culture.

Qualitative research offers a holistic interpretation of detailed processes that have shaped people's lives. The researcher participates intensively in the field work. Researchers turn to people, environments, places and institutions to observe their natural environment. The researcher has the opportunity to collect data directly from the participants through direct encounters with individuals using individual or group interviews or through observations. Qualitative research deals with the opinions, experiences and feelings of the people who produce subjective data.

Qualitative data is rooted in people's daily lives. How they experience and understand the phenomena in their lives. Researchers provide clear information on detailed analysis that shows people's stories about their "real life". This implies that researchers analyse data by presenting people's stories in their own words. Patton and Cochran (2002) claim that qualitative methods are descriptive outcomes aimed at understanding people's experiences and attitudes. This method is aimed at answering questions related to the "what", "how" or "why" of a phenomenon, and not "how much".

4.3.2 Discussing the contribution of anthropological lens in Social Sciences

Russell (2008) is a renowned scholar that has produced publications that differentiate an anthropological research endeavour from other social science research. He argues that anthropological research is special compared to other social science research. For example, sociologists, who work in complex societies, conduct surveys, use structured interviews and administer questionnaires. Sociology usually falls under survey research. Psychologists experiment with patients and thus, Psychology is typically a clinical research. Russell (2008)

declared that anthropologists are area scientists and they learn from their informants. Anthropologists are traditionally recognized to be conducting small scale research, which is centred on unique societies, cultures and lived experiences, drawing largely from unique methods and methods that allow them to conduct holistic research.

4.3.3 The Relevance of Qualitative Methods in Anthropology

Qualitative methods have allowed researchers in anthropology to share in the understandings and life perceptions of others. It has allowed them to explore how people structure and provide meanings to their daily lives. In the opening chapter, the study mentioned that anthropologists take interest in learning about people's experiences and have long stood by the use of qualitative techniques in order to understand them better (Battles 2011). These experiences may include those concerned with people's health or illness or those evoked by their social environment at large but still remain the interest of anthropology. The research interest of the present study rested mainly in the interpretation of a social life context of parents of children with cognitive disability. The research findings being collected and interpreted in accordance with the manner in which they are socially configured or perceived by the participants. Anthropologists have called this gaining an insider or emic perspective. The parents of children who are living with cognitive learning barriers were placed at the centre of this research undertaking for the researcher to learn about their experiences through the collection of meanings.

Qualitative research is said to have specialised tools and techniques that can be used as methods to help in recalling all the important fragments of knowledge, even the small details that might not be important to the participants Lune and Berg (2017). The two scholars supported this argument by referring to qualitative research as an inquiry that is interested in meanings, definitions, characteristics, concepts, symbols, metaphors and descriptions of things. They further postulated that the quality of finings in qualitative methods is obtained through the provision of meanings to life events and things which further enable us to measure the unquantifiable areas of any phenomenon that affect our lives. The flexibility of the approach also allows for the triangulation of methods to enhance quality of findings, especially in such studies where experiences and perspectives are presented in different lenses.

The choice of a qualitative research approach for this study was motivated by the above reasoning which here is re-emphasized as the natural role of enquiry that is concerned mainly

with meaning and interpretation. It is in one breath with a general anthropological study. Interpretivist researchers believe that reality includes the subjective views of the outside world, so that they can adopt an interdisciplinary knowledge of the disease and establish this fact socially. According to Ormston (2014) interpretivists are anti-fundamentalists who believe that there is no right path or single method in knowledge. For this study, a qualitative approach was emphasized to provide insight and relevant information through the analysis of different first-hand data about the subject of the study. Ormiston et al (2014) argue that qualitative research is used to evaluate the relative experiences of human life in relation to their social environment. Qualitative approaches are methods that emphasize the importance of presenting a subjective assessment of information about a person's personal experiences and their social experiences.

In this study which sought to learn about the experiences of parents of children living with learning barrier, I was presented with an opportunity to acknowledge that the views will differ as far as perceptions and experiences are concerned. This admitted to no single truth about the analysis of such topics. This qualitative study approached parents of children with disability to inquire about the characteristics of complex relationships resulting from their children's personal health condition, their immediate environment and the external factors that may determine or define their place within the society. As a result of these complex relationships and considering the social activities associated with development, different environmental factors may impact on the same individual with a given health condition in different ways as (Hartley and Maht 2013) postulated. This was meant to move away from finding knowledge for the sake of knowledge but to take consideration of that knowledge and value it in the attempt to alleviate problems that are felt by communities. Based on this approach, the qualitative study would have provided a complete picture of the whole issue being investigated.

Qualitative researchers are trying not only to better understand their data, but also to understand the consequences of the results and to consider interventions for people on a more personal level. This will highlight the gap between the professional views and the views of the participant on the intervention provided, which can be helpful in interpreting the information (Hartley and Maht 2013). In addition, quality research offers the opportunity to explore the experiences and beliefs of the people in the community to contribute to credibility by prioritizing research values and ethics. Qualitative research serves as a set of alternative ways to explore the experiences of people who are potentially relevant. Therefore, it aims to

find answers to questions about the meaning and personal interpretation of life. It is used to answer open questions about people's attitudes and beliefs in all situations. This allows researchers to demand clarification and examples while exploring the deeper value that goes through those meanings (Lune and Berg 2017). This has led to the use of life history methods in the collection of parental experiences, as described in the next section.

4.4 Defining Sampling

Bradley (2013) defines Sampling as a process whereby the researcher identifies and selects persons to participate in the study. The selected population are considered in a careful way and on the basis that they would answer the questions appropriately and are within the research parameters. The sample comes in a small but carefully chosen group of individuals or objects that represent a wider group or the total population under study. The major objective of sampling is to draw inferences about the unknown population parameters from the known sample (Du ploy et al 2014). Conducting sampling in the research is beneficial in that gathering data on a sample is less costly, more practicable and less time consuming.

4.4.1 Non-probability sampling

The sampling strategy that the study opted for was a non-probability but purposive sampling. Palinkas et al (2015) considers this the most effective for implementation research and provides consistency in the developments of qualitative study methods. Non-probability sampling is a type of sampling used when the sample population is believed to be nearly impossible to determine or when there are difficulties in accessing the entire population for a particular study (Du ploy et al 2014). This was the case with the present study as there were many parents who could have participated in the study, but the study was limited to uMkhambathini and to a particular number of participants (sample size).

The participants were purposefully sampled as they were known to the schools. Prior to finding the 15 participants who constituted the sample, I initially approached the schools to explain the research interest and confirm the type of population that would be needed for participation and achievement of the research objectives. I then requested the school principal whom, with the assistance of class teachers and school administration clerks, wrote letters to the parents to request meetings. In the meetings with parents, I availed myself and the school principal assisted in reiterating and further explaining my research interest and what it entailed to the parents. I then asked for volunteers who would like to participate in the study

as the parents who were in attendance were already parents or custodians of children with cognitive learning barriers. This was stated in the letters of request for meetings as a criterion.

4.4.2 Sampling method

Using a non-probability sampling, which allows researchers to sample concentrated groups, fifteen (15) parents were purposefully sampled and deemed relevant as key narrators in this study. I valued them as important informants because they were parents whose children were part of the formal education system at uMkhambathini. Their deliberate recruitment was not informed by the type of family structures they were in. I understand that both sexes can assume the role of parenting, which meant the consideration of all genders as potential participants. Age was not an inclusion criterion because I had an understanding that those who came to the first meeting were already parents to learners with cognitive disability. Du-Plooy et al. (2014) support the relevance of the intentional model in this study, since they agree that the purposeful model is used when researchers have a descriptive set of characteristics related to the desired data. Purposeful sampling is often used in qualitative research to identify and select in-depth case studies of information or representations of people related to phenomena of interest to researchers..

4.4.3 Recruitment process, study site and gatekeeper processes

Fifteen (15) parents were recruited through three (3) schools, namely, Inkanyezini, Asizenzele and Table Mountain primary schools. I approached the schools prior to the undertaking the research because I wanted to validate what I had observed. This is that there are learners with cognitive disability who attended formal schools instead of special schools and they somehow do not progress like any other normal children. The school principal consented and assisted in setting up a meeting with parents where we met for the first time. The intention of the meeting was to share my research interest and to recruit them as key informants in the study. They volunteered to be part of my data collection and availed themselves to be part of my sample. The school principals and other teachers did not form part of the research sample because the study was not about teaching experiences but parenting experiences. This meant that parents remained the key narrators during data collection. However, this can be another research area left open for other researchers.

Although experiences of parent of children living with cognitive disabilities are never ending and could be sampled from more than 15 participants; the sample of 15 parents that the study sampled was still enough to collect reliable and significance of rich, and real life experiences

of parents. The sampled parents were purposively sampled as they had knowledge and had children who attended in mainstream schools at uMkhambathini. These showed in their willingness to talk about their personal experiences and were open to respond further to the follow-up questions; this gave an abundance of information and opened more factors to consider for analysis, regardless of the sample size. The parents came from three primary schools which are considered larger primary schools in uMkhambathini as they accommodate majority of learners in their respective areas, in broader sight the knowledge that was found and documented in this study could be used to predict and prevent more other issues relating to the topic in the area.

4.5 Data collection

In a previous section, it was argued that the holistic body of this study rested upon finding and interpreting parents' situated experiences about having children with a cognitive learning barrier. In this regard, it is imperative to mention and justify the use of triangulation of methods for data collection in this study. Triangulation in social research is generally looked at as a metaphor used to describe a particular form of multiple operationalism or convergent validation (Ennis and Chen 2012). The term denotes the use of multiple data collection techniques devised to harness a multitude of findings, measure and relate them, as an act of counteracting the threat to validity. In adopting triangulation of methods in this research, I had acknowledged that each parent would be a different facet their contribution to the proposed research questions, such as their role on day to day basis, how they make sense of what is happening and how they have found socialisation although they may have been affected by a similar social reality. I valued the parents as key informants because they are parents whose children are part of a formal education system at uMkhambathini; and they are undergoing different experiences through being parents of children living with cognitive disability in the schools.

4.5.1 Data collection site

To respond to the naturalistic paradigm, which is a crucial element in anthropological studies, I used one of the local school halls to hold the in-depth interviews as well as focus group discussions. These methods of data collection were triangulated to maximize the validity as well as well as the reliability of findings hence the data collection instrument was worded the same. The school principal had already issued a gatekeeper letter. The school was assured

that the data collection will not disturb normal school proceedings, nor will the school principal and the school governing body have access to the research information.

4.5.2 Data collection plenary

Data collection commenced soon after the study received ethical clearance from the University of KwaZulu-Natal's ethics committee. Data collection was planned to take place for ten (10) days with a 30 to 60minute session of in-depth interviews with each participant. Five (5) in-depth interviews were conducted per day, and therefore, all fifteen (15) participants were interviewed within the period of 10 days. This time factor was reasonably considered because I, as a principal investigator, accepted that while data collection is not intended to instigate sad emotions or upset participants, it could happen that parents needed time to process questions. This was observed as participants sighed which signalled their effort to calm down. Secondly, this time factor was meant to allow me as the principal investigator to thoroughly probe with the hope of generating themes for further interpretation in the final write up of the thesis. Although the proposed initial sample size was compromised and reduced to 15 participants, the study was still able to collect quality information to represent the experiences of parents of children living with cognitive disabilities at uMkhambathini. The 15 participants were purposefully sampled as they had experience in the topic that was being research and their willingness to talk about their experiences in-depth provided significance rich insight on real life experiences and reliable responses to the interview questions; both in personal interviews and focus group. The participants came from larger primary schools in uMkhambathini in Inkanyezini, Table Mountain and Asizenzele which accommodate huge number of learners, the experiences could even be predicted for other schools around the area, although variation of such experience and how other parents are impacted is inevitable.

4.5.3 Methods of data collection

Life history interviews and recorded focus groups were used for data collection. The manner that the collection of data proceeded, I interviewed five participants per school in personal interviews. The school and parents as participants had generously agreed to be invited back finish the interviews especially in the cases where we ran out of time. After the personal interviews were finished, I then began to conduct recorded focus group interviews with all five parents per school, and per the day and time that was agreed upon.

4.5.4 Life History Methodology

Life history can be viewed as the narrative or unfolding of a string of events. With realist and constructionist approaches taken into consideration, life history argues that the realist approach has been considered for its interest in historical courses which include social dynamics, generations, and the understandings of social classes and professions (Measor and Sikes 2013). A constructionist approach has been employed to focus on identities, presentations of ideas and narrative configurations. It has a strong belief that a persons' life history must be highly valued as a starting point in understanding their socio-economic structures, which constantly shape their lives. This study is embedded in a constructivist or interpretivist paradigm.

Life history methodologies fit within the constructivist and interpretivists paradigm because as declared by Chilisa and Kawalich (2013) this paradigm allows the researcher to understand the world as others experienced it. It was critical for me to understand how parents who are rearing children with a cognitive disability/learning challenges have experienced their parenting journey. Assumptions of realism differ from those of constructivists in terms of knowledge and their sources, values, and their role in the research process. Constructionists and interpretivists believe that reality is socially constructed. As a result, reality depends on the mind and is a personal or social construct. Constructionists believe that knowledge is subjective because it is socially constructed and depends on the reality that lies in human thinking and experience.

Life history methodology is believed to be an anthropologically pioneered work and was later recognised and applied in various disciplines such as sociology and social psychology (Abdullah et al 2014). In the present century, scholars such as Yap and Majeed (2018) have revisited the approach in their qualitative study about Alzheimer's disease which is a cognitive condition. The study investigated how people with this cognitive condition managed life on a day to day basis. To gather this information, the authors used life history methodology, amongst other methods for data collection, to trace the histories and socialisation of people with Alzheimer in Singapore. Later in the era Bolmage (2014) reproduced a study that was deemed a classical use of life history methodology on a disability case. In the first place, the study acknowledged that caring for people with disability cannot be a definite or normative mission but can, at least, be understood through the collection of the life histories of the people who have experienced the journey.

Through intensive interviews and probing questions, the participants revealed that their socialisation gets increasingly unstable and in most cases is brought to disorganization through ever changing environmental factors. Abdullah et al (2014) continued to stress the relevance of life history methodologies in a qualitative research on the basis of enhanced quality of data. During my data collection process, I sought clarity, probed depth of reasons and asked follow-up questions. The effectiveness of this research methodology is said to have attracted more interest even in the present century having gained more practice from various disciplines such as linguistics, education, geography, clinical psychology and economics; although they have used a variety of ways in their data collection, analysis and overall presentation, which may be slightly different to that of anthropologists (Abdulla et al 2014).

This study is interested in the day-to-day lived experiences of parents, hence the use of life history perspectives. Ormiston et al (2014) argued that qualitative research evaluates the relative experiences of human life in relation to their social experiences. The methodology of life history in qualitative research emphasizes how important it is for the individual to present a relative assessment of their experiences and to provide information about their social experiences. The information collected provides basic evidence of social interaction and action (Dunpath 2010).

This approach plays a role in research aiming for social change, documenting roles, demonstrating socialization and understanding changes within society. The life history approach recognizes the reflection on past and present ecology of social life. (Latif et al 2014). As societies continue to develop and adapt, they live by numerous implicit beliefs and values that frame their thinking and everyday socialisation. Life history has emphasised studying groups that relate to a particular occurring phenomenon and emphasized the importance of regarding their voices, especially those of marginalised groups.

As prompted by the ecological theory, life history as a research design has the advantage of providing historical and subjective depth. This is especially relevant to studies that are concerned with social change, and roles, demonstration of typical socialisation and aim to understand variation within societies. The contemplation of social issues are proposed and aligned with the variation in communities. As life history methodology is in line with qualitative research, personal interviews are conducted and designed as extensive probing and open-ended questions (Measor and Sikes 2013).

4.5.5 Qualitative Interviews and Focus Groups

"The interpretive research paradigm in this study blends with the use of interviews as a source of evidence as this affords one the opportunity of getting to know the participants well and of understanding their feelings" (Mwanna 2007: 88).

The above quote serves to justify that interviews have been used in previous studies on topics concerned with finding personal experiences. This study duplicated such approaches by using interviews in collecting evidence from parents. The triangulation of methods was achieved through personal interviews and guided focus groups. Qualitative interviews are conducted to gain a deeper understanding of their emic perspectives about the research topic (Du ploy et al 2014).

The secondary role that qualitative interviews served for this study was that of maintaining and verifying trustworthiness of data that was collected from previous literature, observations and direct experiences. As argued by Ennis and Chen (2012), conducting qualitative interviews is not only good for collecting information for the sake of it, but can also be an eye opener for researchers, especially to the thoughts, concerns and anxieties of participants (parents in this case) as they unfold their narratives. They further serve as a frame for structuring conversations with the participants to ensure that the depth insights are captured, and underlying meanings are probed as people reflect on issues that impact their lives (Ennis and Chen 2012).

Scholars such as Lune and Berg (2017) agreed to a certain theoretical assumption attached to the identification and selection of methods for data collection. The scholars argued that in designing interviews and arranging meetings with residents in order to solve or understand a social problem, the assumption being made is that reality is constant and stable, and that people can reliably observe and describe it better in perspectives. This was especially argued on the basis that researchers themselves, when making direct observations, leave space for an assumption that events are deeply affected by the actions of all possible participants. It is only then that a research paper will be better presented with descriptive accuracy having been analysed from meanings that are given to events and in the participants' own words and experiences.

Both instruments for data collection consisted of similar questions which were kept as open-ended as possible. However, it was imperative for the study to ensure that the interviews reflected the purpose and the assumptions of the research design. The research interviews

were motivated by the social and contextual circumstances of the study. It was in the essence of both qualitative methods such as life history approach to conduct personal interviews. In so doing I was abled an opportunity to capture real life experiences in the manner that parents perceived and felt how managing a child with a learning barrier have impacted their lives, as (Recklein 2013) had advised. In-depth interviews were also important in prompting prolonged conversation and detailed explanation of the experiences of parents; this was mainly through the development of follow-up questions as I sought clarity.

Furthermore, as a second data collection method, the study sought patterns among cases through the adoption of focus group discussion. The aim was not only to amass data but to have more depth and quality of information where parents engaged more about their personal experiences, feelings and opinions. The rationale was to validate the information as parents were allowed to elaborate their perspectives on the topic as a collective. I had created a supportive environment where parents were allowed to engage their range of common and different points of view on the research questions that ended up providing context for this research. I wanted to achieve the validity of the collected data, and this is accepted in most anthropological research that I have read as part of a literature review process.

The session was predicted not to last for more than forty-five (45) minutes. Fifteen (15) parents were purposively recruited from three schools. This meant that from several parents who volunteered to participate in the study, I had to take up to five parents (5) per school and ended up with a total of fifteen parents as participants who responded to the interviews. A focus group discussion was used as a method for data collection through which parents were afforded a space where they could collectively discuss their lived experiences. I conducted a total of three recorded focus group discussions from each school, as the meetings for data collection were on separate school and on separated dates. This method of data collection allowed me as a researcher to read and record daily experiences for further analysis.

4.5.6 Ethical aspects considered in the study

This study was cleared by the University of KwaZulu-Natal (see the attached ethical clearance) as well as conditions that the clearance came up with. The interviews started off by building a rapport. This was intended to establish trust between myself as the researcher and research participants. As suggested by Ennis and Chen (2012), the quality of data achieved through interviews depends directly on the rapport developed between the researcher and the participants. I found it to be of great importance to take research participants through their

rights as they voluntarily participated in the study. I also took the responsibility to convey to participants that the study solely wanted to understand their experiences regarding the topic and that their views were valuable and useful for all parts of the study. Ethical considerations were taken seriously during data collection and in the process of data analysis. I had taken it upon myself as a researcher to ensure that participants were treated with respect, and I did not make them go through or experience shame, any form of embarrassment. None of the participants reached a point of wanting to withdraw from the study as I kept the question within research plan and avoided any form of humiliation in the way that I probed or in which questions were asked. The wording of data collection instruments was designed to not make researchers experience any stress. I also ensured that all fifteen (15) parents voluntarily participated in the study by encouraging them to sign a consent form which gave a detailed description of the study.

Both data collection sessions had separate consent forms to be signed. The consent form had a clause that stated that participants would undergo an in-depth interview in a schedule that would not need to have original names but pseudo names to identify narratives. As a researcher I specified that the focus group discussion will be recorded so that participants would participate knowing that their voices will be recorded in a tape recorder. I also encouraged them to discontinue with the study should they feel that they were asked questions that created any form of discomfort. However, I tried to avoid such by making sure that I only asked questions that were part of the data collection instrument and refrained from asking questions that were of my personal interest. I probed for further when necessary for clarity, but I was also in a position to study the body expressions of the respondents in order to avoid probing too much.

I also ensured confidentiality by making sure that all narratives were coded or presented with pseudonyms. The storage of raw and processed data was guided by the University of KwaZulu-Natal's ethics board. I used my supervisor's offices to store the data in one of the steel cabinets. I had informed the participants prior to the collection of data that in case any of the participants needed psychological support, I would inform my supervisor and ask her to request the relevant support office from the university where I came from to render such support since I could not afford the services on my own.

4.5.7 Recording and transcription of data

Both interviews and recorded focus group discussions were conducted in designated private places, which were the school halls in Inkanyezini and Table Mountain primary schools, whereas in Asizenzele primary School, it was one of the classrooms within the school premises. The permission for audio-recording of participants in focus groups was requested for and signed separately from those of personal interviews. As a result, the study had two separate forms for signed consent (consent to participate and consent to audio-recoding) and the purpose was constantly reiterated to participants prior to signing the consent forms.

The transcription of information was done in a private room both at home and on campus at the University of KwaZulu-Natal which were my working environments. In transcribing the collected information, I maintained the pseudonyms of participants used in the initial data collection meetings. As advised by Arifin (2018) when doing data collection and prioritizing confidentiality of the data and participants, to avoid the interference and the passing of confidential information to others, I conducted the transcription of data in a private room and when I was in a common room I used my earphones to avoid the possibility of leaking the information. The transcripts and consent documents are protected in a locked cabinet which can only be accessed by my supervisor and I. Until the time of destroying or disposing these documents based on the University of KwaZulu-Natal research governance regulations, the information will remain and maintain confidentiality and anonymity of participants and their information.

4.5.8 Methods of data analysis

The study was assumed as a qualitative research and the manner in which the data was analysed followed the methods of a qualitative research analysis as will be thoroughly detailed in the data analysis chapter. The study sought subjective experiences of parents of children with cognitive learning barriers in uMkhambathini community. The study only had a task of analysing the qualitative data from parents, meaning that there were no objects such as testing machines/equipment or chemical elements or surveying instruments in any of the processes of data collection or analysis. For quality check, I sent out the raw data and the transcripts to my supervisor and two other qualitative researchers for review and confirmation of correspondence.

4.5.9 Validity of research findings in qualitative research

Leung (2015) asserts that validity in qualitative research simply refers to the "appropriateness" of the tools, process and data. It confirms the research question's validity for the desired outcome, and that the choice of methodology is appropriate for answering the research question, the design is valid for the methodology, the sampling and data analysis are appropriate, and that the results and conclusion are valid for the sample and context. The validity of research findings was ascertained by the use life history methodologies as I was interested in collecting experiences of parents who have children that have cognitive disability and learning challenges. I purposively sampled parents because they have the first had experience of raising a child that has a cognitive disability. The validity was ensured by the use of open-ended questions which allowed the collection of emic perspectives, an explanatory model that came through the narratives of experiences from parents. Parents were not objective in the study but subjects. They were the source from which the reliable data were directly solicited.

4.5.10 Reliability of research findings in qualitative research

Leung (2015) states that, reliability is the level of honesty that the researcher embraces during data collection. It speaks to being thorough, careful and honest when conducting interviews, in the wording of interview questions and in the relationship between interviewees and the interviewer. The reliability of research findings can be guaranteed in many levels. The data collection instrument was cleared by the cluster committee and the ethics committee. This compelled me not to deviate to other issues that were not part of the data collection instrument. The good rapport was built through the signing of consent forms with which I was able to take all research participants through what the study was all about and what I expected from them and what they could expect of me. I did not lure them to participate under false pretences such as the mentioning of a token of appreciation at any point in the study. It was clear from the beginning of the research that there will be no sharing or offering of any incentives for participation either before or after data collection. They participated freely, hence the reliability of my findings.

4.5.11 Generalization

Generalization of findings in qualitative research has been debated by scholars. Some say that qualitative research findings do not warrant generalization while others argue that if qualitative researchers know their data, they can safely generalize to a specific sample and

context. Nevertheless, the discussion of level of generalization of research findings in any research is of great importance because the researcher there cannot be a clear context, sampled population as well as an issue that is being studied. Gheondea-Eladi (2014) defines generalization as external validity, meaning the degree to which research findings could be generalized. Leung (2015) states that most qualitative research studies, if not all, are meant to study a specific issue or phenomenon in a certain population or ethnic group, focused locality in a particular context. Thus, qualitative research should not remain limited to the smaller sample that was particularly studied.

Polit and Beck (2010) agree that the goal of qualitative studies is not to generalize but rather to provide a rich, contextualized understanding of some aspects of human experiences through the intensive study of particular issues or cases. Within the scope of this particular study, findings can only be generalized within the scope of parents who participated in the study and where the study was undertaken. This also implies that research findings do not allow transferability to another set of parents but remains the contextual experience of the parents that were sampled for the study.

4.5.12 Experience of the researcher during data collection

Conducting research and completing this paper, I was presented with an opportunity to develop as a growing anthropologist in the field. The pre-planning and conducting fieldwork enhanced my critical thinking and my research skills. In my experience I learned that undertaking any research study could be both an intriguing and humbling journey, which I observed as I came into contact with research participants themselves who trusted me with their daily experiences. I was presented with an abundance of data which demanded massive self-application as a researcher especially that I had to see beyond mere conversation participant; but to look for every fragment in the conversation and participants' demeanours to get depth of meanings for each experience that participants talked about. This research experience has boosted my academic confidence and I am adamant that I have chosen a worthy career path in pursuing one in anthropology.

4.5.13 Limitations of the study

The collection of data was limited to day to day experiences of parents who have children with cognitive disability. Some of the parents were not the biological parents of the children. The study was not gender or age specific in the recruitment of participants. Participation in was open to volunteered parents who had custody of children that attended one of the schools

and also admitted being affected by the research interest. Cognitive disability has been reported by scholars such as Kumar (2016) and Ritzema and Sladeczek (2011) as broad and cannot be judged by observing fewer or one-sided characteristics of behaviour.

The study had proposed and identified a total of 20 parents who volunteered to participate in the study as they also confirmed to have children with a learning challenge in question. However, I ended up with fifteen parents as participants in the study as some parents could not be available on the day for different reasons and some could not be reached when I sent out reminders in a week before the findings were collected. Although some parents could not be available and had not given their consent, the findings of this study were limited to most variety of experiences that could have been discovered in the rural place of uMkhambathini. The study only considered the experiences of parents that were available and who had given and signed consent to participate.

The study relied on parents' experiences and their journey of caring for children with cognitive disability; this was because this study was outside the scope of psychology but within the pedagogies of anthropology. I also did not intend to impose scientific models for diagnosis, and children did not form a part of data collection. Moreover, uMkhambathini is an area with many larg rural communities, and this study was limited to three rural places under uMkhambathini, which are Inkanyezini, iMbungwini and Ingangezwe rural areas. These are the areas where the schools were located and representative of the surrounding communities.

4.6 Conclusion

This chapter has outlined and discussed some important methods for undertaking a qualitative research study. This was to show that a qualitative research design does not only show how to go about conducting a research but also ensures that a true picture of the phenomenon under scrutiny is presented and that validity is ensured (Hyatt 2011). Transferability is provided in the sense that sufficient detail of the context of the fieldwork is clearly described or explained in the manner that it affects the research problem. The study employed a triangulation of methods for data collection, which included recording, guided focus groups and personal interviews. The researcher provides the comparison of perspectives and settings for the readers to compare and contrast the application of the overall information from one environmental situation to the other or the application of this information to other similar settings (Shenton 2014). The study followed and shared the sentiments of a social research

approach which is to prioritise the social setting and place people at the centre of the research. With careful ethical consideration and voluntary consent agreement, the study sampled parents who have children who are living with a cognitive disability within uMkhambathini area as the best possible population to respond to questions posed by this study. The collected data was meant for the purpose of influencing change or possible intervention for parents and their children.

Chapter 5

Data Analysis and Interpretation

5.1 Introduction

This chapter mainly focuses on data analysis. The success of this chapter as depended on theoretical lenses which favoured that the data analysis could be analysed better by means of qualitative data analysis technique. Thematic analysis was used the method of data analysis. It has been mostly used in anthropological studies and has been credited by most scholars who have had interest in studying people's experiences as well as the social construction of factors that lead to a particular experience. Creswell (2007) argued that qualitative research is a means to "allow humans to share their stories, hear their voices in a study". Qualitative data is rooted in people's everyday lives; how they manage and make impression of the phenomena that are happening in their lives. This chapter provides the analysis of data as was performed for the overall study. The data that was analysed responded to the key questions that were designed as part of the ethnography of this research. The study totally relied on personal narratives from parents for analysis. The research paradigm (interpretive) spoke to the symbolism as well as contextualised data. In the viewpoint of symbolic interactionism, the subjective experiences are viewed as symbolic and socially constructed through interaction. In this regard, the sought the collection of experiences of parents with a learning disability in question and the parents were treated as primary source of information.

5.2 Process of Analysis

In this qualitative research, data analysis was undertaken from an inductive reasoning point of view (Du Plooy et al 2014). In the process, the researcher was allowed to develop themes and categories from raw data after the researcher had carefully compared and thoroughly examined the data. This is when a researcher conducts interviews for the purpose of obtaining people's descriptive experiences and trusts the collected data to explain the researched phenomenon, as was the case in this study. The findings relate to the research questions that guided the study and were formulated in accordance with ecological theory as a major theoretical framework.

Data was obtained from Fifteen (15) parents who were purposefully sampled from three primary schools in uMkhambathini rural area. These schools were Inkanyezini primary school, Asizenzele primary school and Table Mountain primary school. The sampled parents were involved in two different sets of data collection sessions. First, the parents agreed to

undergo personal in-depth interviews. Second, the parents were placed together for participation in guided focus group discussions for each school. The data collection process lasted ten (10) days and in each school I was designated a hall for the sessions to ensure that the process of data collection did not interfere with the process of teaching and learning as the data were collected during school working hours.

In analysing the collected data, the study acknowledged and prioritised the massive contribution made by the various body of literature that was consulted for this study. The desired outcome in any anthropological study is the collection of credible, trustworthy, easily interpreted set of data. Thematic analysis was used as the key method for data analysis. Thematic analysis allowed the representation of narratives from sampled parents. Thematic analysis in anthropology is used for eliciting critical insight. Phenomenology influences thematic analysis, considering that this study is made up of a variety of theoretical perspectives affecting the study and narratives which open up a space for diverse concepts to be explained from the narratives of parents (Hyatt 2011).

5.2.1 Familiarization with Data

Having conducted the interviews and guided the focus groups myself, I had the double advantage of collecting data in my language (IsiZulu) and of already knowing the content before I began the painstaking process of data analysis. However, I still had a role of preparing the collected data for proper analysis. This included checking and editing transcripts after I had transcribed the interviews and interpreted the information from the recorded focus groups. As I carefully read through the interviews and listened to the recorded information in preparation to generate codes, I had some moments of reflection and recalled what was said in the interviews, the gestures of participants as they were responding to the questions and the general mood in the sessions. This also helped in familiarizing myself with the data that was collected.

Following a series of interviews and focus groups meetings, I assumed the task of transcribing and translating, word for word, the information from the interview scripts and the recording device as the interviews were conducted fully in IsiZulu language and on IsiZulu-speaking participants. All this was done for a purpose of generating meanings and capturing important descriptive utterances from the responses of parents. Transcribing my own data and revisiting it from time to time also had the added advantage of enabling me to capture a general feeling of the information that I had collected from the interviews and focus

groups. This process made it comfortable for me to write down some reflective notes once I had gotten to understand the material that I had. This is a process which (Du Plooy et al 2014) labelled as *memoing*. The process entailed making reflective notes about what I had deduced from the information that I was reading and coding it, which would help in generating the whole sense the data.

In writing memos, I had made it a point to protect the remarks and questions that were associated to the text that I had read. This was to serve as a reminder of my thoughts and insights during the reading, coding and evaluation of the texts. I always made it a point that I was guided by the research objectives and questions in the sifting of the collected information because the study had a purpose of proceeding to the identification and generating of themes from that would respond to both objectives and key questions that would then assist in solving the overall research problem. I found it imperative to always remind myself of the important research goals and questions as these were always key in determining relevant information to the study topic as they were set give birth to research questions for data collection.

5.2.2 Thematic Coding of Data for this Study

A code is a label that can represent some content or essence of a portion of data (Du Plooy et al 2014). Assigning codes to data varies according to a particular study or the researcher. In assigning codes for this study, my theoretical frameworks and my personal involvement with the parents (participants) during data collection was allowed to influence the coding methods that were chosen for this study (Bingham 2017).

Bingham (2017) notes that it is inevitable for researchers in their analysis and interpretation of qualitative data to always infuse some of their subjective influence in the process such as in the way they generate and assign codes to the data. However, it is advised that to keep in line with and for the sake of productivity during analysis, the researchers must be mindful of their purposes before they decide on coding methods or the overall coding process (Bingham 2017). The purpose of this study was to explore the lived experiences of parents of children living with a cognitive learning disability. I selected the method for analysis that would allow me to yield even the unforeseen aspects of parents' experiences. I started off by using the open coding approach in order to generate and assign codes after having systematically worked on all interview transcripts and focus groups. This meant that all units of data were given enough and equal attention. With this I wanted to avoid pasting data extracts into pre-

existing frameworks. The coding of data was then assigned in accordance with the sense of data that was deduced from the responses of parents.

The study sought to get a general understanding of parents' demographic information at the beginning of interviews. This was in accordance with the initial stage of the ecological theory which is the *micro-system.* The *micro-system* looked at the very beginning of a child's biological nature and direct interaction with their immediate environment, which may include psychological, social and emotional support, family and institutional involvement or participation.

As revealed in the literature review chapter, parents take up the main role bringing up their children which places them in a better position to reflect on the trajectory they have lived throughout the life of caring for a child with a cognitive disability. Seeking participants' demographic information also responded to the *attribute coding* that was employed in this study. More than the demographic information, this type of coding also assisted in revealing all necessary information about the type of data and the details regarding the setting and time of data collection. Bingham (2017) also argued for the importance of attribute coding, saying that it is always helpful getting the correct information about the participants and providing context for each data item which could prove very important in the interpretation of data during the analysis.

5.2.3 Presentation as well as the analysis of Participant's Demographic Information

As I began to transcribe the information that was collected from the parents, I found it important to write all the important attributes of the parents. Although the study was not based on any type of gender or real name disclosure, the ages of parents and/ or any type of families but the parent's demographic information was collected for the purpose of the analysis of a variety of life experiences of parents the parents who volunteered to participate in our initial meeting where I introduced the study were considered as parents to the children in the school and confirmed to be in custody of the children with a cognitive challenge that was being researched.

Taderera and Hall (2017) who confirmed that parent is a person who is in custody of and takes a series of actions to promote the development of a child. Parenting is therefore a process of promoting and supporting the physical, emotional, social, spiritual and intellectual development of a child from infancy to adulthood. Taderera and Hall (2017) postulated that parents do not necessarily have to be a couple caring for the child together but could be a

single parent. As to demonstrate, the questions that were asked as part of the micro-system in the opening of the interviews were meant for background understanding of parents and confirming that they were in custody of any child who attended the school. These questions amongst others included:

- How old is your child and when did you first recognize that your child has a learning/ cognitive disability?
- How did you enroll him or her in that particular school?
- What are his or her learning challenges at school?
- Is your child born in a nuclear, extended or in a single parent household?

The participants were informed beforehand that if their responses to important aspects of the research were not clear, the researcher would ask direct or probing questions such as: what factors did you consider before enrolling your child to this formal school or how did you end up enrolling your child in this school especially given their learning challenge? Have you ever been informed of your child's learning challenge since enrolling them in this school?

5.2.3.1. Gender of research participants:

Gender of participants	Number of their participation
Males	0
Females	15

The table above depict that only women participated in the study and this confirms that females are main caregivers of children as argued by Haihambo and Lightfoot (2010), Kang, Choi and Jin-Ju (2016) in the first two chapters of this thesis.

The following table depict ages in which parents started to parent children with a cognitive disability not their current ages. Roll-Pettersson (2001), Kumar (2016) and Oti-Boadi (2017) independent studies concluded that the process of raising a child with any type of form of a disability is not easy. This following table then informs that research participants experienced this unsupported journey while they were in their early ages. It also indicate that this is the age through which their identity as ordinary women changed and this when their children begun the journey of being excluded or not being accepted by immediate, extended families as well as by the society at large. The collections of these ages were influenced by theoretical perspectives of the Identity Theory discussed in most chapters of this thesis.

Age category	Number of parents in that age category
15-19 years	0

20-24 years	7
25-39 years	8
40-44 years	0
45-49 years	0
50 +	0

5.2.3.2 Family types of research participants:

Anthropologically, a person is born and socialized by a family system which shape his or her identity hence the following data is presented. The Ecological Theory employed to analyse the extent to which families have supported research participants. Detailed experiences are discussed in the following chapters of the thesis:

Family types/categories	Number of participants per family type/categories
Nuclear families	9
Extended families	6

5.2.3.3. Type of parenting as per their family of belonging:

The existing literature in sociology and anthropology has identified an expansion of parenting types over the years. This implies that parenting is no longer the experience of nuclear families/parenting only but other dimensions of parenting have been qualitative and quantitatively recorded. The analysis of data informed that only two research participants benefited from co-parenting as a result of their marriage status. Ten research participants confirmed to be single parenting their parents and emphasis that they are have never gotten married. What the following table depicts is that grandparents who are possible parenting children with cognitive disabilities because of many other reasons did not participate in this study but the study does not imply that don't execute this parenting role in other parts of the world or country where children with cognitive disabilities could be found.

Parenting type	Number of research participant in that parenting type	Marriage status ✓ Yes X No
Co-parenting (husband and wife)	2	✓
Single parenting	10	X
Caregiving parenting	3	X

What also transpired from the table above is that the role of caregiving parenting that was solicited from three research participants. This confirmed that the role of parenting a child with a learning disability is only the responsibility of biological parents but there are other people who have up taking a caregiver role in the parenting process.

5.2.3.4. Number of learners who are observed to be attending formal learning schools while living with cognitive a disability which requires a designated special school.

The following table depicts the number of children with a cognitive disability who have been or are still accommodated by schools which fall in the mainstream of teaching and learning. It is through these schools that I got interest to study experiences of parents whose children have cognitive disabilities and yet they are administrated in a formal/mainstream schooling environment.

Name of the study	Number of learners with cognitive disability attending in that school	School type (formal or special)
Asizenzele Primary School	4	Formal
Inkanyezi Primary School	8	Formal
Table Mountain Primary School	3	Formal
Total number of learners in all 3 schools	15	

5.2.4 Attribute Coding of Responses to Micro-system Interview Questions:

In generating themes from the data that was collected and especially through the questions that were asked in the *micro-system* category, I followed the eight observational techniques of Ryan and Bernard (2013). They signify things to look for when having to deduce themes from data that was collected from participants. These observational techniques are said to guard against listing themes for the sake of doing so and directs a researcher to know what to look for, and to enhance and shape an understanding of all important details presented in the data. This involves paying attention to:

- Repetition

- Indigenous typologies

- Analogies and metaphors

- Transitions

- Similarities and differences

- Linguistic connectors

- Missing data

- Theory-related material

5.2.4.1. The coding of themes

The following theme were developed during the data sifting process which I followed as part of analysing what appeared to significant and relevant to the research objectives as well as theoretical lenses that guided the study. Contributions of scholars such as Kumar (2016), Bingham (2017) as well as Fernandez-Alcantara (2017) were considered in gauging the validity and the reliability of the following themes to inform new insights that are to be contributed by the study. The table below also depict the frequency or the repetition of themes from triangulated methods of data collection being in-depth interviews as a well as a focus group discussion. Such themes informed contextual experiences that are part of a parenting journey for all research participants. Three implied that theme was developed because it came from (3) research participants. While three could appear as an insignificant number to recognise, while conducting in-depth interviews and during the focus group discuss, the body language of these research participants confirmed that they are taking this parenting journey with pride and also echoed that it has own challenges. Fifteen implies that such themes were repeated by all research participants as their daily experience in the journey of parenting children with a cognitive disability. As part of data analysis and interpretation, these themes are developed to depict contextual experiences of research participants and will be aligned with the theoretical contributions of theoretical lenses that shaped the study as well as literature contributions from other scholars cited in most chapters of this thesis.

Themes	Repeated frequency during data collection	
	In-depth interview	Focus group
Female Primary Caregiving Activity	3	3
Parenting of different ages	15	15
Family cultural perspectives and Societal	15	15

views		
Family dilemma and uncertainty	15	15
Self-diagnosis/Inclusive Acceptance	3	12
Attributed Identities	15	15
Burnout and non-disclosure of personal attacks	15	15
Internalization of pressure	15	15
Reiteration and reconstruction of identity	15	15
Burnout and non-disclosure of personal attacks	15	15
Social isolation	15	15
Resilience and Normalization of Identity	15	15
Unjust of inclusive education	15	15
Non-provision of formal intervention	15	15
Promotion of healthy psycho-social awareness in the community	15	15
Unknown problems and contextual research on parent experiences	15	15
Provision of inclusive support/ Generalization of support/learning barriers	15	15
Burnout and non-disclosure of personal attacks	15	15
Internalization of pressure	15	15
Reiteration and reconstruction of identity	15	15

5.3 Thorough Analysis and Interpretation of Experiences of Parents in Accordance with Theories

In the ecological theory of Bronfenbrenner, the developmental context was seen as socially constructed complexities resulting from external influences that are mediated by a person's mind (Ben-David and Nel 2013). It was then said that whatever local environments have on

children must be seen as a direct or indirect influence of how the environmental complexities are perceived and interpreted by parents and children.

5.3.1 Micro-system Analysis of Experiences of Parents

In the case of this study, the smallest setting, which is labeled as the *micro-system,* was taken to be the family organization, as this was the immediate stage containing the developing child. Moreover, this was the start of the holistic consideration of all stages that this study considered as shaping the journey of parents in the rearing and caring for their children with cognitive disability.

After asking the first round of questions, the first volunteered parent from when the interview began in a focus group around *09:04am* on Tuesday the 3ⁿᵈ of March 2020 at Asizenzele school, Philisiwe, reported that *"In this place you never learn about your child's learning disability until after they have been enrolled to one of the schools. From there you get letters or called to a meeting to talk about challenges they face."*

Nonkululeko who was a parent at Inkanyezini responded by saying that *"the child is not mine but both his parents are late/deceased. Now he is my responsibility together with my mother who is his grandmother.* Responding to the question: how old is your child and when did you first recognize that your child has a learning/ cognitive disability? She went on to say that *"the boy was only 11 years old and has always been a quiet child which makes it difficult for us to tell his challenge but I noticed when I looked at his workbook, he writes something like question marks, all his work books have been like that…We always have to hold a meeting with his teachers to discuss whether he should be progressed to the next grade or not. My mother always says that there was no need to worry about his state because it might be the phase that had resulted from the passing of his parents.*

He is still young; he will adjust and start progressing at school once he has acclimatized to the outside world once all rituals have been performed, especially those of cleansing his parents' spirits. To my mother it would seem like disrespecting both our culture and the spirits of the deceased to assume that Boy has a cognitive challenge."

When she was asked about his child's enrolment to the school, Nonkululeko stated that inasmuch as she was suspecting that something was wrong with her boy, she could not skip her mother's decision to have him in an ordinary school setting. She had already spoken to the school principal about the admission of the boy to the school.

In analyzing parenting cases of parents, I deduced a cluster of influences governing the reality of their children which I identified as one of the themes that would particularly come in handy in the understanding of personalized experiences in relation to the research problem. The themes that were generated in the opening interviews and focus group mainly unfolded and focused on the micro-context which revealed the beginning of parents' experiences, which according to findings are invoked by personal diagnosis and self-introspection. Earlier in the literature, Reid-Cunningham (2009) attested to the importance of anthropological emic and etic perspectives especially when the researched phenomenon is to do with human behavior in relation to their social environment.

The scholar mentioned that the use of these perspectives had given valuable information about human behavior from a variety of stand points. The ethnographic lens of this research interest is focused on understanding the crucial experiences of and perspectives on disability, especially those of parents who care for children with a cognitive disability. The significance of questions that were posed to parents in the *micro-system* invoked perspectives from parents in a micro-context point of view.

In one particular instance when I began to analyze responses from a focus group in one the schools, I listened to a recording where *Nomusa* who was one of the parents in Asizenzele primary school, narrated her experience of parenting an eleven-year-old boy. Although may have viewed herself as narrating an ordinary life story, I could glean every key fragment that made up her case of parenting a child with a cognitive disability a challenging one. In the case of *Nomusa,* which was more or less like those of other parents in the other schools, it was found that the enrolment of a child with a cognitive disability begins with a personal or familial conversation laden with a multitude of concerns and uncertainty in the micro-system level. In this instance, the study learned about the influence of families' cultural perspective which included protocol and interaction. Thus, in the *micro-system* context, the study sought to understand and clarify the meanings that parents, as guardians, held prior to the broader exposure of their children to the communal sphere and their involvement as advocates for their children with cognitive learning barriers.

Immediately after the passing of *Boy*'s parents, Nomusa and her mother assumed joint custody of *Boy* as per their micro-culture. Although Nomusa takes full responsibility for the child, as she is registered as a parent in the school that "*Boy"* attended and has to provide all necessities to support both the livelihood of her family and Boy's educational journey.

Nomusa could not overrule her mother's decision to enroll the child in an ordinary school as she is an elder of the family. Although neither could openly accept nor deny a cognitive learning challenge affecting *Boy*'s educational journey, it was Nomusa's mother who encouraged the enrolment of *Boy* to an ordinary school citing that he would fully develop once he has passed the phase of the loss of his parents which has deterred his educational progress.

o *Female Primary Caregiving Activity/Parenting of Different Ages*

Although this was not mentioned as a factor in the literature, in the case of Nomusa, it was deduced that even without parents having to be a married couple, differences in opinions can always be present because parents or child custodians always have to work these out for the greater good of their children. This was to account for cases of over-representation of female parents which was the case with most schools; or the death of parents as was the case with Nomusa's experience.   In most cases the absence of fathers was also reported as increasing the strain on female parents' shoulders. Besides the primary activity of taking care of their children with learning disabilities, fathers were also reported to hinder the progress of the children. Most parents narrated that every child belonged belong to the father's surname and fathers must be forever present in the lives of their children; they have to help the children with cultural rituals such as 'imbeleko' as this might cause problems for children, and affect their learning progress if not observed rightfully. Furthermore, the varied socio-economic statuses of parents, especially the limited involvement of female parents in the workforce might have been a factor in the limited representation of male parents as the interviews were conducted during the day although such questions were not contemplated as part of this study. The study found one particular case in the story of Mrs. Gumede who responded:

"You see my boy, her father is still a young adult, He, got her when he was still in grade 8 but he works now, far from here. So I've assumed the responsibility since then. He is just too scared to admit the problem I see it when he comes, when he gets time off from work. He would always bit about the bush about coming to meetings especially like this one where his child's situation will be discussed. I had discussed about your study after the principal had sent letter to us to come here and just responded by saying that I should be the one going because the school knows me as her parent." Mrs. Gumede narrated.

o *Family dilemma and uncertainty*

At the level of *micro-system* Ben-David and Nel (2013) argue that familial relationships even if it is with one person, remains an essential factor as relationships with our surrounding environment become consistent with our everyday lives as humans l and experiences. The life being of participants in this study was that of parenting a learner or children who identified with a learning disability. The literature revealed that parenting a child with a cognitive disability or any other form of disability is a matter of particular concern, compared to parenting any typically developing child. In a personal interview with Thobekile, a parent of a learner in Asizenzele primary school, when she responded to question that sought learn about her understanding of her child's learning barrier and discovering the learning barrier, she said:

"As a parent it is it was and still is very confusing to tell or to learn that your child has a learning barrier. I can understand with those with a physical challenge but with my son…it is confusing because if he does have this problem I wouldn't know because it is subtle and not very easy to pinpoint. I still can't tell if things are normal or not…I say this because he was accepted in this school without any problems. I see this but his teachers tell me that, can you imagine how hard it must be for me having to find out about this problem from somebody else?"

   o   *Self-diagnosis/ Inclusive Acceptance*

Responding to the same question, Thulisile who was a parent at Inkanyezini primary said that, "*We only learn about these challenges when we are called to meetings when they have to pass or repeat the grade, as this was the case with me. You see with my boy, I know that he is very active and at the same time he is easily angered which has been his constant behavior even at home. Sometimes he is very quiet and sometimes very active. Raising a boy child has an ever-changing nature as you may know…this is something they out-grow in time but I have accepted that he has a challenge because his teachers say so… (sighs…) he fails or get condoned, although I cannot say what is or where is the problem other than that his father has to pay damages because he was born out of wedlock, this I know can disturb a boy child."*

A published article from Learning Disabilities Association of America captioned as *Parenting Children with Learning Disabilities, ADHD, and Related Disorders,* attested to the experience in the above narratives, especially when parents discover their children's learning barriers. Attention deficit or hyperactivity and other related disorders where reported as

characteristic of learners from Asizenzele, Inkanyezini and Table Mountain Primary schools. Likewise, the article in the Learning Disabilities Association of America (Smith 2012) reported such disabilities as the most present in the narratives of parents when having to describe the behaviors of their children with cognitive learning disabilities. It was said that parents are often puzzled by their children who identify with this form of disability, mostly because of their many abilities and disabilities, and also the difficulty in understanding how much of their behavior can be linked to the nature of their condition and how much could be oppositional.

In the birth of every child in the family, which is in the *micro-system,* it was said that parents set their own rules and develop their routines and expectations other than the primary responsibility of ensuring safety and welfare of their children. Such responsibilities are said to be the main source of provocation of discomforting and resentful emotions when parents have to learn about or feel the inadequacy of their children in the process. Self-diagnosis and nondiscriminatory inclusive education had made it difficult for parents to accept or to the least learn about their children's learning disabilities. Lungisile, who was a parent in Asizenzele, spoke about the journey of thoughts she underwent after learning about her daughter's learning challenge, which she traced from the birth of her daughter. As the Learning Disabilities Association of America (Smith 2012) revealed, parents take some amount of time to reminisce and articulate some concerns about their home with their children. Lungisile said,

"My daughter was born a premature. In the early days of my pregnancy I was undergoing a lot of stress especially after I broke up with her father. When the school principal first called me to a meeting to talk about her learning challenges, I could only think about all those incidents because they were always bound to factor in her learning journey. In my eyes she has always been a clever girl and very good with artwork. She only needs more attention because I want her to equally grasp the curriculum and have enough training of her artwork whether in this school or elsewhere.

I even went to her class and demonstrated to the teacher how she like to be taught because as per our home routine. She needs to be pushed and persuaded as I sometimes have to be strict as I had a feeling she was not pushed hard enough in this school," these were the words of Lungisile when she responded in a focus group about how she learnt about her daughters learning challenge.

o *Attributed Identities*

The identity theory earlier argued human beings as species of different identities and interacting with one another in their social spaces. Along the way, they impact and are impacted by their environment, whilst they also ought to predict and create meanings of life events that shape their socio-psychological living. The theory recognizes that people are different in nature and these natural variations determine how they cope in societal endeavors.

This was mainly the cause of skepticism as parents premeditated the next step of the impending exposure of their children especially when they reached school-going age. The majority of children in uMkhambathini schools or in the inclusive learning environment are are normal. The parents of learners with cognitive learning challenges contemplated the treatment of their children in such setting of learning and wondered if they were getting the attention that they required for progressive learning. The issues of identity, especially the sense of belonging of learners with cognitive disability was said to escalate in one way or the other as parents mentioned that other children noticed the difference in the treatment of their children as compared to others. They question and label children with cognitive disability based on how teachers sometimes assist them in learning, as Thulile revealed.

'Some of the teachers empathize with us and they really try to accommodate the situation of our children. Only that the community, even the learners here in the school always insist on making us remember that our children are different from theirs. They are called "abafundi bathisha" (small group that would work with the teacher)' you would find learners after school making deriding little songs about such situation that happens in class," Thulile closed.

The collected data in the *micro-system* indicated that parents of children with cognitive learning barriers begin to experience mixed emotions in a variety of their micro-context domains of their everyday life. Basic structures such as family organization alone can invoke a lot of personal emotions or experiences from parents as it forms a *micro-system* of interaction and containing a developing child prior to the outside world exposure.

5.3.2 Meso-system Analysis of Experiences of Parents

After the analysis of parents' experiences in the micro-system context, the next phase required a look at life beyond a single setting as children with cognitive learning barriers

enter a broader social reality. As argued by Ben-David and Nel (2013), interactions in the *meso-system* and the influence of the reality of objects found in this extended environment can be decisive in the development of children as a series of events taking place within that given setting. Hhow children are affected by such spatial and interactive realities constantly unfold other burden of experiences for parents. In the *meso-system* setting, the study looked at schools and children's ability to thrive. In the questions that were asked to parent in the *meso-system,* dependent factors such as community and perceptions were considered because relationships are formed and cultured within such factors of the socio-environment. The following questions were relevant to the meso-system level of analysis:

- What are your personal and day to day experiences that you can share as a result of having a child with a learning/ cognitive disability?
- What ways do you try or have tried as a parent to deal with hardship experiences that come as a result of having a child with a cognitive barrier?
- How do you go about supporting your child's educational progress both at home and at school?

The questions that were posed in the *meso-system* sought a general impression of what parents experienced and did to manage life on a day to day basis. The questions were kept as open-ended as possible to allow an in-depth reflection on experiences. The life history approach which was used as one of the methods for data collection had a huge significance in allowing a free-flowing conversation with the parents. Parents pointed out some concerns about the identities of their children based on their self-diagnosis and the explanations they attached to their cases as they try to normalize their situation. They faced the pressure to normalize their children's identity together with theirs as they are known to their communities as parent of children with disabilities. This was discovered in both personal interviews and focus groups as over ten (10) of the sampled parents grieved over the reiteration and the reconstruction of the identity of their children, more especially. Golubovic (2010) attested that all different cultures make context and essential social living which would then provide a culture-based way of living in a similar manner that it would shape thinking.

The definitions and interpretations of their identities were derived mostly from such cultural frameworks. In the meso-system, parents revealed being conceptualized differently as a common factor amongst them. Having listened to their narratives and assessed them in

accordance with such cultural paradigm, I was able to understand what being a parent of a child with disability or being a child with a cognitive disability meant in the socio-cultural context of uMkhambathini as a rural place, and the ideological connotation it carried. The themes that were generated were in close reference with the cultural paradigm of uMkhambathini, especially their adaptation and socialization within the community.

Themes Generated from the Responses of Parents in the Meso-system:

- *Burnout and non-disclosure of personal attacks*
- *Internalization of pressure*
- *Reiteration and reconstruction of identity*
- *Burnout and non-disclosure of personal attacks*

In a focus group at Inkanyezini primary school, Zinhle added that it was not that they did not appreciate the inclusive education and what it could do for their children. However, the constant meetings and having to discuss the incapability of their children brought continuous stress. She elaborated on the burnout they experience due to their children's learning processes in mainstream schools. The feeling of difference and not belonging was constantly re-emphasized as detailed earlier by the social identity theory.

o *Reiteration and reconstruction of identity*

Earlier in the discussion of identity theoretical framework Battles (2011) reckoned that socio-cultural schemas go beyond the visible perceptual occurrences; they could go as far as serving as explanatory devices and rationalising tools for social relationships. Thus, social identities are embedded in such socio-cultural context.

"Now everybody in this community knows that when I am going to or coming from the school, it must be about my daughter even if it's not. As I was coming to this meeting, I met my neighbor who asked: Usenzeni-ke untombazane wakho manje?(What has your daughter done now?). You see it is very stressful having to always explain yourself to people about confident matters as these. Some will even tell you that if you tried finding schools in the cities you wouldn't have to play this game of up and down, as if this was any easy…", as Zinhle narrated.

The experiences presented in the *meso-system* were a testament to literature as McDonald et al (2015) argued that parents of children with a cognitive learning barrier or mental disability

generally, would have a significant amount of parenting stress. They went on to elaborate the correlation between such amount of stress level and their children's developments. This was said in terms of the expansion of developmental relations as noted by Mantey (2014:27) who argued that "This suggests that, children with disabilities may come from supportive environments, which provides effective care, support and kind behavior to them at home. Once the child goes to school, the linkages between home and school for the child, and the new transactions with teachers, peers, classmates, workers, and managers will have developmentally influential effects on the child." On the part of parents, this may demand more of coping strategies and trial of various defense mechanisms. This study had contemplated asking such questions in order to understand how parents attempt to contain such demanding conditions.

Other parents resorted to coming to terms with their child's challenges as one of the ways they try to cope and, in some instance; they would plead with their siblings and friends who attend the same school as their children to watch over them as they commute to and from school, and over the school period. In the literature Roll-Pettersson (2011) provided some writing on coping strategies that parents sometimes desperately try being influenced by a series of events resulting from the socialization of their children with disabilities, which in turn influence their perceptions. Such was evident in the case of Nokulunga who revealed that she had even sought help from her church.

"personally I have even went on to consult with people of spiritual gifts like in my church, we have such people and they have always mentioned that my son will have challenges because his father has not paid damages as he was born out of marriage. So what I try to do is to pray that these challenges he faces especially those affecting his education might just go away in the meantime especially while waiting for his father to do the right things… because there is a lot that needs to be done from my side and his fathers. After church services I ask my pastor and few members to pray for me and the situation with my child." These were the words of Nokulunga.

Sabeliwe, like Mrs. Mdluli, both parents at Table Mountain Primary, responded that they had tried to change schools in uMkhambathini, which were both non-special schools. This was meant to provide for a change of environment for their children who had been failing at the other schools. Mrs. Mdluli mentioned that in her case, she always tried to work with the teacher by updating them about the situation of her granddaughter whenever they had to

change schools. She tried to check the progress and attended every possible meeting that was scheduled by the school, although not very often.

- o *Internalization of pressure*

As has been stated in the literature, parents of children with a cognitive disability mostly cope with their child's learning barriers through internalization. This was a direct and indirect modal response across interviews and focus groups from the three schools (Thwala et al. 2015). In these responses, they would mention seeking God's grace and courage, accepting the children as they are. Most methods of dealing with the hardships that parents experienced were generated from personal or parental instincts. It was only one parent out of fifteen sampled parents who reported having sought professional help for her child, and to have her child removed from the mainstream setting in order to protect her. She had seen psychologists and also consulted with social workers for different opinions based on their expertise. However, the process was uncompleted as she had to access their offices in the cities from the rural area, which proved difficult at times as she was living on limited means. Another problem she had was that of the complexity of routines which were also uncompleted and eventually, she gave up the attempt.

5.3.3 Analysis of Experiences of Parents in Exo-system

Themes Generated from Responses of Parents in the Exo-system:

- *Social isolation*
- *Resilience and Normalization of Identity*
- *Unjust of inclusive education*

Mantey (2014) and Härkönen (2017) provided their respective literature in *Accessibility to inclusive education for children with disabilities: a case of two selected areas in Ghana* and *The Bronfenbrenner ecological systems theory of human development,* which showed the linkage and complexity of processes that are taking place in the *exo-system*. The *exo-system* was said to be symbolic of activities occurring in two or more life settings. Despite the fact that one of the contained settings does not necessarily have a developing person, but only the events that are taking place in that particular setting, it tends to cause an impact on an environment containing the person that is developing. The study was centered around the narratives of parents of children with a cognitive disability in Mkhambathini which is a rural place. In this rural setting, there was an observed evidence of the lack of special schools to

support learners who could not be fully included in the learning system of an ordinary public school, hence the examination of the narratives of parents in order to understand the situation of development of their children. The questions that were asked in the *exo-system* had mostly to do with factors such as parents' home situation in relation to social statuses and social activities, education of their children and neighborhood traditional standards.

- What are familial and societal pressures do you receive as a result of your child's condition?
- What is your identity/ societal labels that your child has received for the family or the society as a result of having a learning/ cognitive disability?
- What parental skills that you must use in order to cope with everyday/ identity challenges that you face through the situation of your child?
- What kind of support do you receive from your communal institutions, religion or nuclear or extended family, if any
- What are your current views regarding the education system in view of your children learning/cognitive disability?

o *Social isolation*

This is one significant factor that was attributed to the social realities in identity theory. Self-isolation or social isolation was reported as a resultant factor that was mostly prompted by social grouping and the awareness of difference, as most parents were always skeptical about their identity and status within their communities. This highlights that individual impairments are carried on to learning environments and tend to influence the learning participation of their children. According to School for All (2002), disability is an impairment which disables ta child, creating discrimination and barriers to participation, in this case, and educational participation.

When the respondents were asked questions about familial and social pressures that they received as parents of children with disability, they mostly reported social isolation as the main pressure. Most of the parents from the three (3) schools reported that full inclusion remained an illusion in the area, and it only gets worse. They get social labels and mixed reactions from their families, communities, friends and relatives. The journey of having a child with a cognitive challenge was perceived as a lonely one. Some even argued that socializing is made harder because the topic of parenting a child with a learning challenge is always bound to come up. Although some people in the community may be or appear to be supportive, but they cannot be always available all the time to offer their support.

Parents felt these limits through attitudes that were directed at them, especially in social gatherings that included family gatherings, parent meetings in schools, and even in churches services. This was felt as making the social life difficult and preventing them from living a normal life as they felt excluded from their societies. Some attitudes to the children with disabilities are among barriers preventing families from leading ordinary life as they are excluded from the community. Thwala et al (2015) cited Gona Mung'ala-Odera, Newton, & Hartley (2010) who in their work indicated that families of children with disabilities find themselves in the margins of their societies and restricted in the access of services and at the receiving end of negative attitudes. Also, they are still expected to overcome such challenges and secure the required support, which does not happen without prejudice and the encounter of more isolating reasons.

- *Resilience and Normalization of Identity*

Parents try different ways to deal with the pressures of society. Raising children with cognitive learning barriers revealed that coping strategies and defense mechanisms are mostly in place. Most parents in the study could not clearly pin-point the type of a learning challenge that their children were identified, with or in some cases admit these challenges. They attributed them to impending cultural rites and were always aware and had the experience of parenting that was not normalized within their communities. This is why they are prepared to maintain their identity together with their children.

"You possible can't do anything…I have accepted the situation. What I do is to keep my son on a positive mind especially when he comes from school. He would sometimes report to me that he met some people who called him this and that but I just tell him that he must never listen to what people say, I would then check for home works and help him to work on those just so he doesn't dwell on those thoughts" Nonkululeko responded to a personal interview.

- *Unjust of inclusive education*

When responding to the question on what were their day to day experiences as a result of having a child with a cognitive learning barrier, most parents felt underserved by the process of the inclusive education which is the only choice that they have in the rural uMkhambathini. Stress, anger and frustration were a common emotion from parents and across most expressions of daily life experiences. This was evident in their demeanor as they elaborated their stories. Rosemary, who was a parent at Inkanyezini primary school,

particularized her case of demotivation. She mostly lamented the acceptance of her son in the school and having informed the teachers of the concerns she had prior to the enrolment, only to later receive countless letters and attend meetings from time to time to discuss challenges faced by her son. She viewed the acceptance and lack of improvement in her son's situation as dishonesty within the process. She responded to day to day challenges that she faced because of the situation of her child as being at the receiving end of all sort of societal pressures.

"*You are never at any rest as a parent of a child as mine. I always feel like each day is a reverse because you are always reminded of their identity… we talk to teachers about the concerns as to let them know about their situation prior to their enrolment into the schools, with my son I even directed the teachers on what to do in order to plead with him and to get him to do the work…they accepted him but only to find out months later that he is not coping. Sometimes they will call us to a meeting to talk about referring them the special schools in town.*"

The children with cognitive learning disability could aspire to a fulfilling life as they were seen by their parents. However, they grieved over the hindrances especially that is resulting from the lack of support in their societies. There were also concerns about the future of their children mostly because they have learnt about the continuous cycle of exclusion as education beyond high school was rarely a case in uMkhambathini. Leonard (2011) reported that a required synergy for support should offer and be centered on the important overlying cycles that determine communal interactions from families, schools, involvement of communities and teachers or school administrators. These factors were mentioned as affecting the exo-system of a developing child whether the child is a participant in or not. The scholar went on to stress the importance of a close watch and constantly thinking them over as they and their procedures influence the environment wherein the person grows to become a fully-fledged member of the community.

5.3.4 Analysis of Experiences of Parents in Macro-system

The last of the four concentric systems that formed a frame for data analysis in this study is the macro-system. As cited by Mantey (2014) in Bronfenbrenner, macro-system is inclusive of all the previous three states (*micro, meso and the exo-system*) of the ecological theory. This study mainly drew on the *macro-system* as provided by Harkonen (2017) who cited the original author to argue that 'the macro-system consists of an overarching pattern of micro-,

meso-, and exosystems characteristic of a particular culture, subculture, or other broader social context, with particular reference to the developmental-inspired belief systems, resources, hazards, lifestyles, opportunities, lifestyle options and social interchange patterns embedded in each of these systems.' These perspectives and influences on the development and socialization of people affected by disability were given broader analysis, after having been looked within these circles of the environment within which these people are in active interrelations. The embedment of disability within social reality was based on the three significant assumptions about their environment (Harkonen 2017). These include:

- Person as an active player, exerting influence on his/her environment,
- Environment as compelling person to adapt to its conditions and restrictions
- Environment as understood to consist of different size entities that are placed one inside another, of their reciprocal relationships.

The research questions in the macro-system were carefully asked in line with the consideration of the impacts of the environment on a broader social context. The set of questions was naturally kept open-ended and cognizant with the significant assumptions of the active interaction of people in relation to their environment and mostly, in relation to all facets of the ecological theory of development as laid out by Harkonen (2017):

- What form of formal intervention do you receive to help you and your child cope with the situation if any and what aspect of change would you like to see?
- What are your current views regarding the education system in view of your children learning/cognitive disability?
- What can you recommend which could help all children experiencing the same disability challenge?

Themes that were generated in the Macro-system:

- *Non-provision of formal intervention*
- *Promotion of healthy psycho-social awareness in the community*
- *Unknown problems and Better research on parent experiences*
- *Provision of inclusive support/ Generalization of support/learning barriers*

- o *Non-provision of formal intervention*

"After learning about her condition, I took her to the psychologists where she went through a series of test and I took counseling for a month, because the school or the department does not provide any. She was found to be okay and I brought her back here but the teachers keep on saying that she is not coping in this environment. I even tried to look for a school that could accommodate her situation but I went without any success."

Parents responded by arguing that their problems were not known, hence the lack of supportive intervention. Out of the three schools, it was only the group of parents at Inkanyezini primary school who reported having a referral program administered by the school principal. Once the child has been identified as having a learning challenge the school called a meeting with a concerned parent to discuss the situation whereby, they would be advised to consider and assist parents to find a special school in town. This was highly commended by the parents as a provision of choice. Although they reported that it was not an easily decided transition as three parents of the five parents who had been notified about the program in the school still opted to keep their children in mainstream, stressing more unforeseen difficulties and challenges with the process in the long term. The study was led to believe that this was not a form of formal help as it was not generally implemented in all schools. Lungisile took it upon herself to seek professional intervention as she had always been concerned about her daughter being born pre-maturely.

o *Promotion of healthy psycho-social awareness in the community*

Parents advocated for education of their communities. They argued that things such as help regarding inclusive support do not come because people are not accepting. They get scared to talk about the challenges because most people treat the issue of disability as a curse or disgrace. Some level of awareness was needed to bring about the sense of community and to rethink the cultural beliefs about disability in Mkhambathini, as parents said it was still surrounded by stigma and prejudice. Having a child with disabilities is associated with punishment, curses and failures.

"This has to start with us as parents in uMkhambathini. You see, the inclusive support and trained teachers must come as a support that we have advocated for. Parents I am saying this because today I am 46 years old but I have never seen or heard of people who fight for such problems in this community. Yes we need support from education but it should find us ready to accept and implement without having to worry about finger pointing and labels", Nokulunga responded in a focus group at Table Mountain primary school.

o   *Unknown problems and Better research on parent experiences*

Responding to the question: what are your current views regarding the education system in view of your children's learning/cognitive disability? A general impression was that of lack of support regarding the education system, especially the support of learners with disability. The reasons put forward were those of concern about the already overcrowded classrooms, lack of physical services within the school, lack of trained teachers and lack of consistent monitoring of the situation from the Department of Education. These conditions were said to have been made unfavorable for inclusion. The consideration of the role of culture in shaping family beliefs and community understanding of developmental disabilities was said to be overlooked in the system of education, as parents reported lack of proper enactment of these factors in education system.

"I also wish they could just come to us (sighs), I don't know whether to say teachers or the people from the department of education. But they need to know about our challenges and grievances just so they can see what we go through or the type of assistance that we plead for because we get scared to talk about these things even in our parents' meetings. The teachers never understand when we talk about these challenges in association with the impending cultural rituals, they see us as if we are running away from our problems." responded to clarify some of the challenges that are not considered in the education system. Parents felt that there was a need for education personnel to try and learn about their unknown problems through better research on parents' day to day experiences.

o   *Provision of inclusive support/ Generalization of support/learning barriers*

'They need to come to us, maybe that way they can even be able to see that we cannot afford schools elsewhere because of our home situations as some of us do not work, those that assist children with this problem. The only nearby school in this area is for physically challenged learners which is why they end up here because it won't make sense to put them there.

I noticed that with most parents of children such as mine in this area as we speak as we know each other in the community, they will tell you that the children pass a few grades and the next few years you will see them being out of school doing nothing."

Although parenting of children with cognitive learning barrier is viewed as a difficult journey for parents and highly stigmatized, parents of such children still showed readiness to talk about their varying experiences. Other than being care-givers to their children with

disabilities, they also proved to be cognizant and observers of their environment as they narrated what has happened and what needed to be done in attending to issues related to learning disability in rural areas as reflected in the above narratives.

In the instances where such concerns were raised, I asked a probing follow-up question which was to gain more clarity on what parents were hoping to achieve through personal research about their day to day lived experiences. A general feeling among parents was that the lack of support was due to the gaps and the generalization of disability. This was demonstrated by some parents, especially at Inkayezini and Table Mountain, which were the two schools that had recently undergone renovations. Parents argued that the physical structures had been made more conducive for learners who had physical challenges and those who might present with physical challenges in the future. However, this could not be generalized for learners with cognitive disability as their challenges could not be presented as obvious. It was in such cases that the study deduced that parents needed some element of choice, that in as much as they faced difficulties in learning about and admitting that their children have a cognitive challenge, they equally needed special schools in their areas as demonstrated in the following diagram.

Figure 5.3.4.1: The Circle Diagram of Learners with a Cognitive Disability in uMlkhambathini from the experiences of parents:
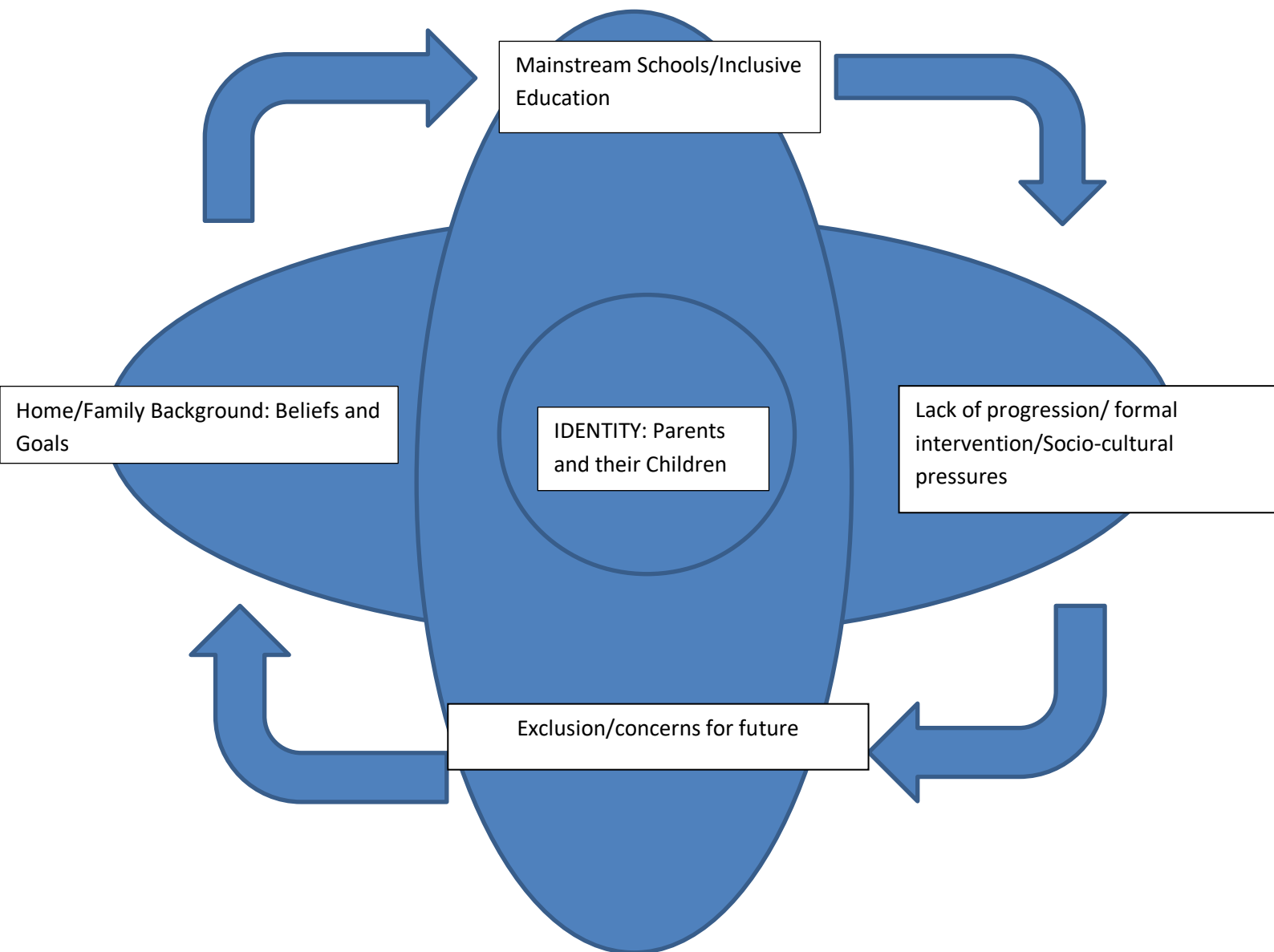
The circle depicts the trajectory of parents and children with cognitive learning barriers in uMkhambathini. The diagram was drawn with a close reference to the four stages of the ecological theory as a major theory in this study. The diagram also reflects the analysis of the experiences of parents, and it indicates how their children are affected by their environment in uMkhambathini through lack of special schools and insufficient inclusive support in mainstream schools where their children attend.

1. At the center of the ecology, the diagram shows the nurturing relationship of parents and children with cognitive disability. Parents at this stage parents care and raise their children while trying to cope and get used to the identity of their children.

2. As the children grow, they begin to interact with other members of the family and other members of society. They begin to show some skill sets and interests in different activities which would raise hopes for parents regardless of their identities or family background. All parents want to see their children growing to become fully-fledged members of society and learning achieve their goals and participating in the social activities.

3. The children grow up and reach the school going age, where they have to be enrolled in a school to fulfill their education. In uMkhambathini the parents of children with cognitive learning barriers are compelled to send in their children in mainstream schools despite their identity or depth of their learning condition, as in the area where the study was conducted there are no special schools available. Some parents also reported that it is at this stage where they discover about their children's learning conditions although they still cannot afford to look for better accommodating schools in Pietermaritzburg City.

4. Due to lack of special schools and insufficient inclusive support in uMkhambathini, the children end up not progressing further with not only their education but the stigma and stereotypes attached to disability in the rural place of uMkhambathini, some parents even choose to withdraw their children from the schools, limit participation or general socialization of children.

5. Parents of children with cognitive learning barriers were most concerned about the above mentioned forms of exclusions and mostly, the future of children in uMkhambathini who live with cognitive learning challenges, they were mostly concerned about when will the situation be resolved and where will the children go for fulfillment of their education and what will they become in the future.

5.4 Conclusion

The literature provided the definition and an anthropological theoretical context within which knowledge of disability has been understudied (Reid-Cunningham 2019). The anthropological understanding and the interpretation of disability revealed a close association with the concept of "the other" and typically, the deviance and stigma that continuously plague the interpretation of human behavior in any given social environment. Golubovic (2010) further expanded this literature by arguing that when enclosed into a community that is defined by an identity, the concept of identity then becomes an ideological construction especially to determine a natural community. To minor identities such as those of disability, this would create frustrations and a distorted sense of belonging, and mostly creates a

symbolic exclusion of those minor identities within one community as drawn in the following concluding analysis diagram.

Chapter 6

Presentation and Discussion of Findings

6.1 Introduction

The themes that were created in the previous chapter were used to formulate a summative thematic presentation of findings. However, they were still re-introduced as sub-themes along with the discussion of relevant findings. The study ended-up with four categories under which the final data was presented after the analysis process, all in accordance with the ecological theory which was a principal theory for this study. The revelation of the theories was that of the significance of a turn of life events in the ecology where children with disabilities develop. The findings were indicative that disability was not only a personal biological identity lodged in the body, it was also being created by material and social conditions that limit full participation of individuals and families who are affected. Many parents presented their cases as constantly experiencing struggles of identity, finding the balance within visible social inequalities and managing resulting stigmas.

6.1.1 Re-emphasis of Questions and Objectives

The study sought to understand the practicality and to conceptualize the experiences of parents of children with cognitive learning barriers who attended mainstream schools in uMkhambathini. The collection of demographics by this study gave a demonstration that disability varies, and we cannot shy away from noting that there are people living with a particular disability in our families and within the community at large. As a result, the country has attempted to implement the Inclusive Education Policy which has allowed learners with disability to be included within the system regardless of their identities, which was an effort that was enormously appreciated by parents during the collection of data. However, it was found in this study that societies in rural places still await an education system that caters and provide schools for all children living with disabilities. uMkhambathini as a deep rural area has children who are not supposed to be attending mainstream schools.

The key questions and objectives were set and guided by the important stages of the ecological theory, which aimed to cover all significant aspects of the journey of parents regarding the topic of this study as demonstrated below. The planning of research questions in this qualitative study was affected by the placement of the ecological theory (Creswell 2009). Creswell (2009) argues that in research studies, especially those affected by cultural

themes and theoretical perspective, the principal theory must be consistent with the collected data and or the perspectives of participants; hence the alignment of theory in the setting of research questions and analysis of data. The study had the following objectives and questions to be fulfilled after data collection and analysis as outlined in the opening chapter to:

o Explore the lived experiences of parents of children with cognitive learning barriers on daily basis, from the rural place in question.
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o Learn if parents get any form of support in raising children with cognitive learning barriers, individual or institutional support and the nature of support.

o Learn about parent's view of the future regarding the learning condition and the situation of their children

Research Questions;

The key questions were developed from the research objectives and in accordance with the theoretical framework that was used in the study. The key questions that were asked for the achievement of research objectives were:

o What challenges do parents of children with cognitive learning barriers face due to the children's need for learning on daily basis?

o What kind of support do parents of children with cognitive learning barriers receive in raising and supporting their children?

o What opinions/views that parents of children with cognitive learning barriers have regarding the future of learning and the condition of their children?

6.1.2 The Role and Contribution of Experiences of Parents

The Lived experiences of parents amounted to a greater value and are critical in the contextualization and addressing socio-cultural problems as stakeholders. Parents were held as important figures in the formulation of the research problem, their varied experiences were also found to be important in the contemplation of solutions aimed at lifting the problem. It was also found that using an anthropological ethnographic inquiry in understanding the embedment of disability within social reality and valuing the situated knowledge as emptied

in the natural setting could set aside roles of collaborative agents and ascertain a holistic stakeholder involvement in systems change, such as in formulation and implementation of inclusive policies. This is the contribution that was made by this study; especially because parents bemoaned that the little that was provided within inclusion remained exclusive of the consideration of their narratives which has also been thin on the anthropological research ground.

6.2 Discussion of Results According to Main Themes

As demonstrate in the previous chapter, after the collection of findings I then served a qualitative thematic analysis of responses from parents in order to find organizational and conceptual connections in the experiences of parents regarding the research topic. From the broad themes, I then identified and outlined sub-themes that were discussed and proved to be contributing to the experiences of parents. All themes and sub-themes that were generated were believed to carry an important implication for each case of participants.

6.2.1 Micro-system: Cluster of Influences

- **Sub-themes:**, *Family cultural perspectives, Family dilemma and uncertainty, Self-diagnosis/ Inclusive Acceptance, Female Primary Caregiving Activity, Parenting of different ages*

- *Family cultural perspectives.*

In studying the experiences of parents in the *micro-system,* I learned about a multitude of influences prior to the exposure of a child to the outside world. The influences in this study were divided into two categories, one of which was *influences of the identity of the child within the family.* The understanding behind this category was within the discovery or identification of a child with disability and acceptance. A cognitive disability is not a type of disability that is obviously observed. In most cases parents had an attached explanation of their children's learning barriers, such as restless spirits of late parents, children being born out of wedlock and impending payment of damages.

Haihambo and Lightfoot (2010) literature contribution in chapter two indicated that discovering that a child has a particular disability invokes some internal debates where parents begin to ask questions about the discovered fate or the cause of fate although they may not be able to find answers. These scholars indicated in their study that parents daily ask

them questions which are not known and supported by families as well as the society at large. Such questions are: where will the child go for any form of education empowerment? How will the child be accepted and cope while attending school? How will I protect his or her identity or how will I prepare him or her to accept his or her identity?

- *Family dilemma and uncertainty*

On the other side where problems were suspected, parents still had hope and wanted to give their children a chance to learn in mainstream schools, which was to assess if they could develop fully overtime. Some parents only discovered after their children had been enrolled to a formal school that their children had a cognitive learning barrier. The second part of influences was labeled as *influences on deciding the child's education*. Parents remained hopeful even after discovering their children's barriers. They still contemplated and dreamed of the best education for their children. This was revealed from the first question that was asked to parents as a confirmation of having a child with a cognitive disability who attended one of the schools, and the follow-up question which sought to learn about the first time that parents identified or discovered their children's learning disabilities.

- *Self-diagnosis/ Inclusive Acceptance*

The local schools in uMkhambathini have maximized access opportunities to all learners irrespective of their learning barriers or challenges to realize constitutional right. Such schools operate under or within an inclusive approach. Despite direct or indirect acknowledgement of a child's disabilities as per diagnosis of parents, they still expected some degree of vocational teaching which would prepare children for the enhancement of skills in order to serve a certain role in society.

However, the inclusive acceptance has made it difficult for parents to choose or advocate for proper education that would fully support the learning needs of their children. The absence of special schools and inclusive policy in this rural place has created a normality of accepting and enrolling children with a cognitive learning barrier into mainstream schools. Parents tended to ignore the signs of disability in the hope of inclusive education. In some cases, parents were not even aware of the inclusive education and its purpose to the point of accepting that their children did not progress because they were failing to learn the curricular rather than having a learning barrier.

- *Female Primary Caregiving Activity*

The study learned about the influences of child caring activities which impacted the educational journey of the children, although it came as an unexpected factor in the research. The evident over-representation of female parents from the time when the research interest was introduced, up to the stage of data collection, the study gleaned the lack of micro-context support from male counterparts. Although in some cases, the absence of male parents was reported as a result of intense involvement in workforce, other female parents were equally involved in workforce but had asked for time out to attend the meetings especially because the identity and education of their children was the topic of the time and they wanted to contribute to the issue.

The parents bemoaned the everyday strain felt on their shoulders, having to be caught between attending to the well-being of the family or household duties while having to be wary of sudden need to attend to meetings concerning the disability of their children. Most participants mentioned during interviews that they were single, unemployed parents, that they could not make more means of self-intervention. They could only send their children to accessible mainstream schools and find ways to cope with the situation.

- *Parenting of different ages*

The study found a need to learn about parents in their homes for the purpose of understanding the types of parenting and what parenting of different age means, especially if intervention for the assistance of parents is to be made and inclusive of all factors associated with the pressures of parenting.

Ethnographic studies and literature from Taderera and Hall (2017), Reid-Cunningham (2009) and While Mak et al (2010) confirmed that parenting gives one a social/ symbolic identity, role and status over his or her offspring. Study findings confirmed that the stigma attached to learners with a cognitive disability does not only affect the discredited learners but extends to the individuals that are closely related to the stigmatized children. Parents were listed as being the closest and on the receiving end as societal misconceptions blame them for giving birth to disabled children. Such social, symbolic identities, roles and statuses of parents are sometimes overwhelming, especially when a parent is faced with the responsibility of having to rear, accept and socialize a child with any form of disability.

Young parents were visibly absent from meetings during this study. Those who were present reported the pressure that they faced within their communities especially from their peer-age

parents, which contributed to the fear of attending meetings concerning the learning disabilities of their children or accepting the disability of their children. From such scenarios, the study gleaned the misrepresentation of learning disabilities as linked to the fear of societal pressures and the stigmas attached to people with disability. Parents were even forced to try-out and risk enrolling their children into mainstream schools as a way of showing to the society that their children were not as disabled as the society had put them out to be, but only experienced minor problems linked to culture and stresses experienced during pregnancy and would improve overtime.

6.2.2 Meso-system: Coping and Adopting Coping Mechanisms

- ***Sub-themes***: *Burnout and non-disclosure of personal attacks, Internalization of pressure, Reiteration and reconstruction of identity*

- Burnout and non-disclosure of personal attacks

What are your personal and day to day experiences that you can share as a result of having a child with a learning/ cognitive disability?

The journey of caring for a child with disability is restless and burdensome. Other than having to face the difficulty of accepting that their children have learning disabilities, parents are generally not involved in the process of inclusion. As a result, they experience countless mixed emotions in their journey of parenting children with cognitive disabilities. Parents felt that they were not prepared for the process of inclusion and are frustrated by the back and forth meetings to discuss the identity of their children.

Although parents appeared to be coy about disclosing the personal attacks they received as a result of having children with cognitive disabilities, disability identity has not been normalized within the community of uMkhambathini. Parents reported stigmas attached to it and that the situation only gets worse with the lack of interventions, including that of the general education of communities about the existence and inevitability of such identity. In the interlude of trying to accept the situation of their children, parents are caught in the mix of roles and adapting to the situation of caring for children with cognitive disabilities. Their everyday lives are spent in changing routines, trying to deal with challenging behaviors from their communities and trying to find balance in the absence of inclusive of support.

What ways do you try or have tried as a parent to deal with hardship experiences that come as a result of having a child with a cognitive barrier?

- Internalization of pressure

The internalization of pressure comes as a result of not being able to defeat the cultural beliefs of the society and the reality that their children have learning barriers. The depth of responses of parents alluded to the depth of emotions of sadness and disappointment which they experienced, especially because these emotions were usually kept inside and rarely had immediate solutions. Mostly, parents felt that sending their children to mainstream schools reversed the journey of acceptance as they received feedback which reiterate the disability and forced them to relook the condition of their children. Thus, parents even encouraged children to play alone even in their absence and away from other children. As Zinhle from Inkanyezini primary school stated:

'You know, every time when she is coming from school she reports that she does not play with anyone anymore and I sought of agreed to that because she said that other children called her with names that I can't even say here because I no longer want to feel what I felt…I saw it was better if she did not played with anyone because I do not want her to miss school because of that. She has such challenges, but she sees when something that is said to her is not okay'.

On daily basis, parents have to constantly try to ease the pressure on them and their children by maintaining positive adaptive measures such as teaching their children to ignore the prevailing negative forces or comments from the society, and that in doing so they will pass their grades and move to the following classes. Other parents took strong restrictive and protective measures in shielding their children from what they called "danger". They taught their children to get used to isolation in order to avoid negativity from their peers. '*I tell my son to go straight from home school and straight from school to come home. I have even advised him to sit alone during breaks and on weekends I spend time with him and do homework together, anything to avoid the negativity form peers and outside school premises.* Parents take such measures or become over-protective of their children and themselves as a result of shyness and anxiety due to the identity of their children.

How do you go about supporting your child's educational progress both at home and at school?

-   Reiteration and reconstruction of identity

The parents of children with cognitive learning barriers are expected to do more in accessing and supporting their children's educational progress which constantly remind them of the challenges of their children. Their everyday dealings have to be planned carefully whether their children are with them or at school. Most parents were not sure whether they were doing enough to support their children and most of them felt that when going an extra mile, they will be doing too much especially for a condition with unknown limits. Some parents took the initiative of routinely going to the respective schools to inform the teachers about the learning challenges of their children. This was to check for improvement and advising the teachers on controlling their behavior to make their children become 'teachable' as Nonkululeko stated.

'I try to do a little that I can. Only that with their condition you end up not knowing if you are doing enough or what is right or wrong, like if I want to punish her…because I used to do that but it was not helping. Now I just report to the teachers and try to advise them of the ways that I sometimes use at home when we learn together. She wants us to learn together and she wants to believe that…Because she sees when I do not answer the question first, there has to be a mommy answer and hers will follow and this applies every time we do schoolwork. I do that I can day by day.'

Thwala et al (2015: 214) argued that parents are better acquainted with their children and are able to inform the teachers about the learning problems of their children. They can help teachers better understand their children, provide advice on individual behaviours, and help design and implement joint learning support strategies. The above quote shows that the emic narratives of parents are to be taken seriously when policies for the betterment of children with learning barriers are contemplated and implemented.

Thulile responded by saying that *'I speak to the teachers when they call me to meetings and sometimes, I come to the school myself. I tell them that my son easily feel bothered when given too much attention especially when he is made to focus on one thing he gets upset. If I want to get him to learn something I do it with a very careful attention to his changing attitude then I stop and go, stop and go all the time. But I am not sure if this can happen here.'*

The impression that was general from all three schools was that parents complained about some efforts that did not bear any favorable outcomes and reported constraints towards

helping their children with learning barriers as being the inconsistency between the efforts tried at home and the continuity in their school. They then extended a view that schools must have trained teachers because the resident teachers in the mainstream schools are not hired for learners who needed special attention. Parents had a strong belief that strategies and ideas that they sometimes try at home in getting their children to learn and dealing with some difficulties can be shared for the improvement of the situation.

6.2.3 Exo-system: Broader Social Isolation

- ***Sub-themes:*** *Social isolation, Resilience and Normalization of Identity, Unjust of inclusive education*

What are familial and societal pressures do you receive as a result of your child's condition? And what is your identity/ societal labels that you and your child have received from the family or the society as a result of having a learning/ cognitive disability?

- Social isolation

In one of the focus group gatherings at Inkanyezini primary school, parents were vividly seen to be disappointed, and expressed their disappointment in saying that their children are forever isolated, directly or indirectly judged and ridiculed. A sentiment that was especially shared between Zinhle and Rosemary was that*, the children are always counted out of educational events such as debates that the school would occasionally host. This was reported as paining because the two parents expected their children to be tested across all activities that take place in the process of leaning.*

There was an evident skepticism when parents were asked to mention the kind of pressures that they received from either their families or within their communities as a result of having children with cognitive learning challenges. Instead parents preferred to talk about what lacked in the quality of life within their families and communities which isolated and denied children the opportunities to become fully-fledged members of the community. This is as a result of the perception that people with disability are a single minority group (Reid-Cunningham 2009). Such findings were indicative that parents learn to accept at different in paces and that disability itself cannot be a total hindrance as their children were capable of adapting to some teaching methods.

However, the beliefs of the society and lack of necessary help brought about hindrances and isolating factors, which is when parents started to feel pressured to do more. The barriers that

these children faced were the results of exclusion from their communities. The lack of resources at school level resulted in emotional stress that was evident for most parents. Reid-Cunningham (2009), described people with disabilities as being restricted in their communities because their bodies or mental conditions restrict their ability to achieve "independence, self-reliance and personal autonomy and are socially excluded. He expanded to say, they are taken as objects of care not as complete human beings who must be trusted with opportunities to make their lives better.

Likewise, the socially and structurally inaccessible resources and lack of formal intervention proved to be the major factors contributing to broader exclusion of people with disability in uMkhambathini. The experiences of parents indicated that the education system in the rural area was not designed for the full participation of their children with cognitive learning barriers, while families and the larger community tended to blame and stigmatize them for the behavior of their children. The inverse across all four stages of the ecology and developing children with cognitive disability is symbolic of exclusive culture. Parents felt excluded from their families, schools and the society as the majority of abled children and society tended to respond with an attitude of exclusion. It was revealed in this study that the organization of knowledge and belief systems reflects interactions between culture and formal structures, and imperceptible cultural norms and values.

What parental skills that you must use in order to cope with everyday/ identity challenges that you face through the situation of your child?

- Resilience and Normalization of Identity

The study found that internalization, as a tool or method to deal with societal pressure, proved to be an important coping strategy for parents of children with disabilities especially in rural areas such as uMkhambathini. Some of the parents said when they feel that the burden is beyond them, they simply pleaded to God to give them the strength and resolution they needed. The findings attested to the work of (Thwala et al 2015) who cited Heinemann (2002) on parents' resilience, coping and future expectations on disability. In the study it was said that parents of children with a cognitive disability tend to react in an emotionally and physiologically negative way to the diagnosis of their child's barrier. However, in time they would develop coping strategies which include being spiritual, courageous and learning to accept their children with disabilities.

Bongiwe said that, *for me is to only help my son with his education. Every day I check for homework and try to check his progress through asking his friends some questions because they will tell me of his struggles that they might have witnessed in class or what teachers said about him. I do not want to stay much on what people have to say.*

Bongiwe was rather concerned about the future over what people say about her child: *I do not care much about what people have to say as they will always have some things to say about me or my son but my biggest worry is that he might end up like many other children in this area who have the same problem...we see, they end up roaming around the place and being ridiculed by people her.*

It was evident from the findings that the problem of learning disability has existed for a long time in uMkhambathini and forced parents to get used to the pressures of society. Cultural beliefs played a major role in overlooking people considered to be disabled. Communities have always looked at disability as different from typical development of the majority, viewing disability as a lesser form of human nature (Thwala et al 2015).

What kind of support do you receive from your communal institutions, religion or nuclear or extended family, if any?

- Continued Isolation

Taderera and Hall (2017) indicated that, challenges faced by parents of children with a cognitive learning disability are exacerbated by factors such as community attitudes, cultural beliefs as well as institutional challenges. When the participants were asked to talk about the forms of support they received from various institutions that are in existence in their ecology, a majority of parents stated that isolation continued to prevail as there was no reported formal support in almost all of the communal entities. Parents reported isolation from the community, friends, relatives and even churches, limiting their time of socialization to finding ways of keeping their children in educational spaces and providing self-protection of identity.

'A few of community members try to understand our situation and they would comfort you where they can, but nobody really wants to be always bothered by stories that aren't really affect them. Other than coming forward when our churches pray for general issues there is no constant support that I can recall especially in our area. Sometimes people can be supportive sometimes they cannot be.'

Thwala et al (2015: 213) cited A study by Gona, Mung'la-Odera, Newton and Hartley (2010) in Kenya which found that families with children with disabilities were left out of society due to lack of services and negative attitudes. The cited literature extended sentiments shared in the findings of this study. This is that caring for a child with a learning challenge prevented families from living an ordinary life while the lack of support slowly excluded them from their communities even without their awareness, as most of their time was spent in trying to provide necessary attention to their children. The learning disability in uMkhambathini is symbolically lacking social activism while social discrimination and the embedment of disability in social reality remain complex and enduring as the findings revealed.

What are your current views regarding the education system in view of your children learning/cognitive disability?

- Unjust inclusive education and the Importance of support

Parents appreciate inclusive education policy in that it attempts to eliminate communal segregation and discrimination through the creation of accommodating learning environment. However, the arising issues of socially stigmatized parents of learners with disability continue to create regression and exclusion of their children in the mainstream education system. The narratives of parents on their children with cognitive disability showed concerns that, despite lack of special schools in the area, the education sector did not provide adequate support for inclusive learning. These instances could only mean more mixed emotions and more pressure, especially because most of them were single parents from poor backgrounds.

The interviews revealed that parents of children with learning barriers had financial problems which were mostly part of the reasons why they ended up enrolling their children into accessible mainstream schools as they could not afford special education elsewhere. The responses of parents were in line with what the literature from Mantey (2014) had to say that raising a child with disability could mean emotional and financial cost, especially when they are born into poor families. A collective voice from all parents, especially from focus group engagements participants, expressed that they want their children to experience full participation as any other children be it in classroom or through extra mural activities in their socio-cultural environment. However, the inclusive program has not allowed such to happen in uMkhambathini as the program is mostly plagued with frustrations.

Thulile said that, *Although I am happy with this inclusion and what it can do for most children who do not have such problems as my son. You see my son is almost eleven years now but he does not grasp anything that is learnt here and I feel he is not pushed enough. I like other parents I know here we are always called to meetings to discuss whether they should be progressed to the next grade or not. It is tiring…*

The view of this study was that iinclusion in uMkhambathini is mostly distorted as it depends on the practicality of the situation of a disabled learner and could only achieve social justice through an integrated learning environment but does not guarantee enough curriculum attainment to achieve promotion of a learner to the next level, based on the views of parents.

6.2.4 Macro-system: Contextualized Intervention

Sub-themes: *Non-provision of formal intervention, Promotion of healthy psycho-social awareness in the community, Unknown problems and Better research on parent experiences, Provision of inclusive support/ Generalization of support/learning barriers*

What form of formal intervention do you receive to help you and your child cope with the situation if any and what aspect of change would you like to see?

- Non-provision of formal intervention and Promotion of healthy psycho-social awareness in the community

Although the journey of parenting a child with cognitive disability spans a multitude of emotions and social isolation, it was found in this study that parents learn to accept and talk about their life stories over time. Parents are ready to share their experiences and their views of how they can be assisted, and even the role they can play in the process of intervention. The life stories of parents revealed beliefs and concerns about the process of inclusion placement experiences in uMkhambathini. They saw a need for professionals to be culturally wary of the practices and treatments that they employ for their children and to help them feel comfortable enough to share these experiences freely. These were the suggestions that would help parents experience lessened stress and further bring about a more efficient course of care between professionals and the parents together with their children.

This study reveals that Mkhambathini remains at the receiving end of attitudes and stigmas that are directed to people with disability, even in the present day. This was reported evidence from parents' narrative especially about the way they have been treated. Parents reported the lack of supportive entities such as organization of activism and perceived cultural norms and

values. This study argues that effective inclusion would require a human right-based and socially modeled approach.

Planned solutions must be able to identify barriers and come up with proper interventions and also address attitudes of culture, environmental and organizational change for the purpose of holistic consideration. The communities in uMkhambathini as many other communities across the country, has not normalized the disability identity which promotes the perceptions that it is a curse from God or bad omen resulting from various cultural dysfunctions. To facilitate effective inclusion and inclusive support that would promote change in attitudes, beliefs and values, communities must adopt consistent positive habits such as activism as pursuit for long term commitment to normalize disability.

What are your current views regarding the education system in view of your children learning/cognitive disability?

- Unknown problems and Better research on parent experiences

The findings recommend that future research must focus on conducting in-depth interviews and rounded research to open a platform for parents to share their feelings, experiences, beliefs and concerns about inclusion while maintaining on-going collection of feedback. In the *macro-system* as the outmost environmental stage and in relation with the case of developing children, the literature revealed that it held within it the cultural beliefs, laws and traditions. Berk (2000) wrote that if in a specific culture it is believed that bringing-up children is the parents´ task then evidently this culture will not provide much help to the parents in their educational efforts. This in turn affects the parents´ educational environment and their chances to deal with the task of education.

This encapsulates the case study of uMkhambathini as it is reflective of the reality of the rural area in relation to the challenges faced by the parents of learners living with cognitive learning barriers. Having revealed the instances of what parents grieve over in the previous circles of the ecological theory, the first question that was asked in the macro-system sought to understand the provision that exist for the purpose of intervention to assist parents together with their children in their educational journey. The literature had revealed that although primary early childhood intervention may be the last thing on the minds of parents as they go through mixed emotions of sorrows, vulnerability, disturbances and dilemmas at the diagnosis of their children's disabilities, they need professionals to save them on their

downfalls, to listen to their sorrows, to dry their tears and formulate supportive pathways forward.

What can you recommend which could help all children experiencing the same disability challenge?

- Provision of inclusive support/ Generalization of support/learning barriers

The first-person narratives of parents revealed that they experience more difficulties within their social ecology as their children get more exposure to broader spheres of their environment. The challenges are exacerbated by the cultural norms and values of either the immediate family or the broader society. The cultural beliefs of families with children who identify with a cognitive disability goes on to influence the decision-making of parents especially in relation to what educational journey should be taken and what purpose it should achieve. Also, the kind of support that parents receive is a dependent factor within the environment. It was argued that the transition within any family living with a disabled child brings about significant changes, a positive change if the family is accepting, and isolation or exclusion results if the family belief system is not accommodative of the existence of disability (Ravidran and Myers 2011).

Parents wanted to be included in decision-making where the future of their children is concerned. A cognitive disability, a feeling of "otherness" from parents of concerned children appeared to be common from all parents who felt like the identity of their children play a role in social differences. In the collection of data, they recounted the lack of either therapeutic or empathic support for them together with their children to comfort the situation, especially because the literature likens the birth of a child with a disability to a continuous period of grief. This was mainly for the reasons that life histories and qualitative presentation of social experiences have not been put into thorough research and the consideration of these subjective evaluations have not been placed in the place of priority when formulating interventions.

6.3 Relevance and Contribution of the Study

The definition of anthropology in the early chapter portrayed the discipline as taking interest in learning about people from their past to the present. In the past life the discipline had difficulties in locating a firm place in studying the cognitive part of human society. This is believed to have led to fewer studies inquiring about types of disabilities and the impacts it

has among human societies. Furthermore, cognitive anthropology as a distinctive area of interest is relatively new, as it could be dated back to the early 1960s (Blount 2011). The discipline needed a definitive facet and a standing position that is distinguishable from psychology (Blount 2011).

Anthropology recognizes culture as an integral part of human life carried throughout the life-long development of humans. Anthropology has accepted disability as a human trait that impacts human societies and any social environment (Kumar 2016). Children with disabilities are born to parents or families who are not independent of their culture as their relationships to each other and broader society is operative under cultural norms and beliefs, directly or indirectly. Sometimes such relationships and interactions are shaped by elements of culture. This study was approached with a holism approach of anthropology. Holism is looked at in anthropology as holding an assumption that inter-relationship among parts of a certain subject is inclusive of biological and cultural features. This approach is then used in the undertaking of studies that are concerned with perceptions, behaviours, spiritual and emotional changes that are experienced by human societies.

This study found that the underlying concerning experiences of parents are mostly situated in the rational fear or concerns about the future in terms of the acceptance and social stigmas attached to identity. The parents of children with cognitive disability worry about the adverse outcomes as a result of a lack of accommodative policy to support the learning barriers of their children. Parents experience or feel forms of exclusion and, or isolation due to not being accommodated within their environment, and their communities view them as not belonging as they become a symbolic minority with a particular identity.

The lack of studies such as this in uMkhambathini has resulted in a failure to address issues experienced by the society. So has the lack of social activism advocating for the accommodation of cognitive disability within the interest of education. The communities experience such issues in their social environments as a result of their culture. Parents pleaded that their voices must be heard and should inform the amendment of educational policy regarding education of children with cognitive learning barriers. This is for the sake of normalising the effects and the solutions must be made available within the same socio-cultural environment in order to create a holistic and accommodative culture.

6.4 Discussion of findings

The use of the Ecological Theory, Identity Theory as well as qualitative research methods located the research in the world of parents who are raising children with a cognitive learning. Experiences of parents showed that their socialisation was enormously plagued by constructed social identities and societal stigmas associated with the identity of their children. Parents find themselves in-between trying to address the fights of identity for their children and attempting to achieve a normal identity seemed to be unachievable. Their societies are insistent on creating and isolating the disability culture through stigmas and failure to recognise the needs of their children. The participants felt that the inclusion in education was captive and does little to prepare for later life. Parents as representatives of their children and broader families felt that they were not given a chance to evaluate the inclusion program as they constantly complained that most people with a cognitive disability in the area do not become fully-fledge members of the society.

Parents have considered sending their children to these accessible formal schools but most of their children do not make it to grade seven (7). Those who are able to progress to grade seven (7) do not make it further. This regression of learners worsen the burden carried by parents whom, regardless of their child's disabilities, still expected some degree of vocational teaching which would prepare them for the enhancement of skills in order to serve certain roles in society (Kumar 2015). This has promoted the treatment of the disability community as weaker social beings and the overall embedment of disability as different from typical developing others. They are seen as less human to the extent that they receive negative social names such as *'izinkubela, okhalipha, ongqonjwana'* especially because initiatives or interventions to assist their abilities are rarely provided. In such cases parents are forced to gradually accept their situation regardless of its heaviness.

6.4.1. Study perspectives of the learning Support in South Africa

The South African case study indicates the lack of proper consideration of the elements of identity theory and ecological theory in the formulation and implementation of policy, hence the prevalence of issues associated with learning disability. The South African education is framed and governed in the Admission to Ordinary School policy and the South African Schools Act 84 of 1996 (Republic of South Africa, 1996) as recognized in the Bill of Rights. The Admission Policy to Ordinary Public School (1998) and South African Schools Act (1996) as constitutional support policies, provide a shared sentiment in that they are both for

non-discrimination in the admission of learners with special education needs unless there are compelling reasons to do otherwise. However, problems with the recognition of parents, learner diversity and quality education remain elusive to curb despite such benchmarks.

One of the mandates of South African democracy was to rally behind and commit to the transformation of education system. This would be made by the government accessible to all, regardless of social statuses and identities. The country has since moved towards the adoption of inclusive education (White Paper6, 2001) to allow the effect of a global consensus of inclusion which aimed at creating accommodating educational environments regardless of social identities. However, the implementation of the initiative in the country has shared the characteristics of previous disparity. People with disability remain excluded from educational activities through lack of necessary provisions.

6.5 Conclusion

The presentation of findings was made in a constant comparison between the contributions of theoretical frameworks, the literature that is was discussed in the previous chapters of the thesis. Theoretical frameworks as well as qualitative research methods are praised for allowing the research collect the emic perspectives, narratives or experiences of parents who participated in this study. Despite the debates surrounding disability, whether in the form of social definitions, constructions and misconceptions, parents were found to be prepared to share their experiences, especially for the purpose of getting desired assistance. The parents reported a multitude of causes of concern regarding the identity of their children in the rural setting. Their journey of acceptance of the condition of their children was always challenged by the social reception and restrictions found in their ecology of development. Parents were mostly concerned about the educational journey of their children, which was the immediate phase of life after the cluster of influences in the *micro-system*. Most pressures and fears of parents were coming from the place of broadened exclusion from almost all spheres of their environment as intervention to support learners with cognitive disability was not provided for while awaiting long-term intervention.

Chapter 7

Contributions, Recommendations and Conclusion

7.1 Introduction

This study was conducted to collect experiences of parents who are parenting children with cognitive disabilities and who have been observed to be attending mainstream/formal education where the study was conducted. This study was conducted within the scope of anthropology which studies human kinds. The study was shaped by significant theoretical lenses, the Ecological Theory as well as the Identity Theory. These theories have been used in anthropological studies to study contextual experiences. The generation of data was made possible by the employment of qualitative research methods. The use of in-depth interviews as a well as a focus group discussion allowed the researcher to be immersed in the world parents who are parenting children with a cognitive disability. This closing chapter offers recommendations based on the findings of this study.

7.2 Contributions of the study

This anthropological study contributes the following into the exiting body of knowledge:

- This anthropological qualitative study contribute experiences of parents at UMkhambathini where the study was conducted who were sampled because they were observed to be raising children with a cognitive disability which hinders them to be part of a family system, societal system and evidently not accommodated by education policies because of their geographical location.
- The Circle Diagram of Learners with a Cognitive Disability in uMkhambathini from the experiences of parents

The theories and literature sources provided sequential framework for learning about such processes in the environment, it directed the integration and the analysis of data as ((Hartley and Maht 2013) was adamant that this should always be the case, especially when the research paper is meant for the purpose of translating into solution in the future. This study also wanted to lay out data that will be solution to future researchers and makers of public policy to understand what identity whether collective or personal expresses in different socio-historical environment and to consider the meanings and impacts when they have to provide appropriate solutions that target inclusive social participation. The meeting point of this anthropological study and the use of the ecological theory is the realization that people represent the socio-cultural of an environment in which they live and function. Parents of

children that are living with a cognitive disability exist in an environment in which education of children is emphasized and is provide a basic human right. In such environment, an anthropological consideration would advocate for provisions to accommodate all members of schooling as a culture regardless of bodily state of being; as education would be made common ground.

The collection of the experiences of parents in this study contributes to the professional scholarship of anthropology by showing that the identity of disability is equally important as that of persons who are considered normal. Parents of children with cognitive disability embraced their children and equally desired full engagement of their children in social activities and aspired to see them developing whole personhood. The educational aspect of life is presumed to be one of the determining factors of human life and proves to be a culture on its own, or impact culture. People find and derive meanings in education. Among the many meanings derived from education are the value of improving knowledge, ways of living and the betterment of the socio-economic status of human societies.

7.3. Recommendations

This anthropological study did not at first want to create an impression neither that South African inclusive education has been a complete failure nor that it has not provided any change in the situation of children with cognitive learning barriers or solution to some extent of child development. Findings revealed that South Africa government has not make a holistic provision of schools that cater for the inclusiveness of children with cognitive disability hence there is a need to invest in such rural schools. Studies that seek to find experiences of people living with disabilities or parenting experiences especially in rural communities will not any soon reach the level of saturation because of how disability as a phenomenon is interpreted, how people with disabilities are treated, and the lack of a holistic support from families as well as the society at large. More qualitative studies are recommended so that experiences of those that are directly and indirectly affected by any type of disability will be captured in order to inform response policies as well as development interventions and other empowering programs (Berk 2000). Continued qualitative research studies, government interventions will largely respond to deeming social constructions and misconceptions of disability identity that stigmatize parents as well as children who did not chose to born with a specific type of disabilities. The South African Government as the level of local government should expedite professional immediate interventions while awaiting

long term intervention from the department of education either at a provincial or national level.

Parents in the study are off the view that current policies continues to produce regression and exclusion of their children in mainstream education. Parents reported distortion in the inclusion process as it seemed to depend on the practicality of the situation of a disabled learner and could only achieve social justice through an integrated learning environment but does not guarantee curriculum attainment that is enough to achieve the promotion of a learner to the next level. Parents where the study was conducted are praying for an inclusive education policy as well as development interventions which will eliminate communal segregation and discrimination through the creation of accommodating learning environments. They strongly believe that absence of inclusive policies that accommodate their children in the education system as well as development interventions in the form of awareness campaigns will continue to socially stigmatized parents of learners with disability.

The manner in which disability among people has been explained and categorized makes one to conclude that it is condition that causes a division amongst people. Where there is a division amongst people there is a greater possibility that one will have access while the access of the other is limited, compromised or distorted by some conditions.

7.2.1 The Nature of Support Desired by Parents

- *Frequent therapy and coping strategies (societal-wide development interventions);*
- *Addition of special schools within the rural area to provide options for learning in the long term;*
- *Professional structures for the submission of grievances and monitoring of learning challenges and that which will support them as parents;*
- *Inclusion of trained teachers for learning disability within mainstream schools;*
- *Social activism and unity for normalisation of disability/learning disability.*

Future studies may react to the direct consultative role of anthropology in the making of policy regarding inclusive environments, including in educational spaces. This should be done in the capacity of holism, given that anthropology is a discipline that is concerned with the holistic nature, time, and transition of human societies. Such studies may fill most voids that exist and have future implications for support-based interventions for people with disability.

7.3 Conclusion

The principal theories in this study played a central role in delineating the cause of adversity of relationships within one environment. The lack of provisions and society's failure in accounting for the needs of people with cognitive disability creates and influences a multitude of forms of social exclusions and cultural stigmatization. As various literature and findings of this study demonstrate, people with disability have been described as restricted because their bodies or mental conditions have restricted their ability to achieve independence, self-reliance and personal autonomy and they are socially excluded. In all spheres of the ecology, parents are constantly affected by the embedment of disability in being caregivers and decision makers of their children, hence the research interest.

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UNIVERSITY OF ™
KWAZULU-NATAL

INYUVESI
YAKWAZULU-NATALI

17 December 2019

Mr Mxolisi Gwwala (214540947)
School of Social science
Pietermaritzburg Campus

Dear Mr Gwala,

Appendix A: Ethical Clearance
Protocol reference number : HSS/0581/019M
Project title: Exploring the Lived Experiences of Parents of Children with Cognitive learning barriers at uMkhambathini

Approval Notification – Full Committee Reviewed Protocol
This letter serves to notify you that your response received on 29 November 2019 to our letter of 29 October 2019 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

This approval is valid for one year until 17 December 2020.
To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

Yours sincerely,

Dr Shamila Naidoo (Acting Chair)

/ms

cc Supervisor: Dr Balungile Zondi
cc Academic Leader Research: Prof Uma Mahesvari Naidu
cc School Administrator: Ms Nancy Mudau

INKANYEZINI PRIMARY SCHOOL

POSTAL ADDRESS
P.O. BOX 14017
PIETERMARITZBURG
3200

TELEPHONE
033 390 9045
E-mail
kanyezini@yahoo.com

ARISE AND SHINE

Appendix B: Gatekeeper Clearance

D1000 Rd

Inkanyezini Location

PIETERMARITZBURG

3201

082 7170 744

03-08-2018

Mr Mxolisi Gwala

Masters degree (Anthropology)

University of KwaZulu-Natal

Dear Mxolisi

This letter serves to confirm that you have been granted permission to conduct your research study at Inkanyezini Primary School as you requested. I acknowledge that your proposed study targets parents of learners affected by your research topic which are known to this school and you wish to be assisted in identifying them given their consent to participate in your study.

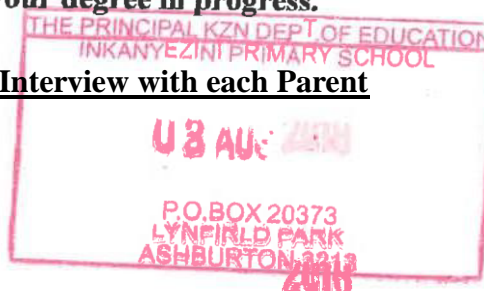**Appendix C: In-depth interview data collection instrument**

I wish you well towards the completion of your degree in progress.

Personal/In-depth Interview with each Parent

Opening

Yours Sincerely

T.G Vezi (Principal)

A. Hello, my name is Mxolisi Gwala. Thank you for availing yourself and consenting to take part in this interview for my research study.

B. The research is about Exploring the Lived Experiences of Parents of Children with Cognitive Learning Barriers in this place (uMkhambathini). As a parent that is concerned in this research topic, I like to ask you a few questions that are based on your experience about caring for a child who have this learning barrier and attending in mainstream school.

C. Your contribution is very important and will be solemnly used for the purpose of completing this research as part of my Master's degree. I also hope that the discovery of such knowledge will help this community for better changes in the future.

D. This interview may take up 30 minutes of your time; do you agree to stay for this duration?

I will begin by asking your name although you are allowed to use any pseudonym if you wish to withhold your real name.

Name (Pseudonym):

Body

Interview Questions:

1. Do you have a child who has a cognitive learning barrier who attends in this school?
_____
_____
_____
_____

2. Is your child a boy or a girl child?

_____
_____
_____
_____

3. How old is your child and when did you first notice that your child has a cognitive learning challenge?

_____
_____
_____
_____

4. What is the name of the school where your child attends?

_____
_____
_____
_____

5. Why did you consider sending him/her to this school?

_____
_____
_____
_____

6. What challenges does he/she face in his/her learning in the school where he/she attends?

_____
_____
_____
_____

7. What type of a family structure was your child born into, was he/she born in within nuclear/marriage/single parent/ extended family or raised by the relatives?

_____
_____
_____
_____

8. What personal experiences that you have on daily basis that you can share regarding the condition of your child?

_____
_____
_____
_____

9. What personal interventions/ways have you taken/tried to help you cope with the daily challenges that you face as a result of your child's learning barrier?

_____
_____
_____
_____

10. What do you do on daily basis to help the learning progress of your child both at home and in the school where he/she attends?

_____
_____
_____
_____

11. Is there any help that you receive from any of your communal institutions such as your church or your extended family?

_____
_____
_____
_____

12. What pressures/challenges do you face in your community due to your child's learning barrier?

_____
_____
_____
_____

13. What personal measures do you take to deal with the pressure/challenges you face due to your child's learning barrier, and do you go about trying to protect your child and yourself from such pressures/challenges from the society?

_____
_____
_____
_____

14. What formal interventions have you taken/do you take to help your child progress despite the condition he/she has and what type of change do you wish to see in the future?

_____
_____
_____
_____

15. What is your opinion regarding education in this place, especially with regards to the condition of your child?

_____
_____
_____
_____

16. What intervention can you mention and desire to see that would help all learners with cognitive learning barriers on their education in this place?

_____
_____
_____
_____

Closing

Is there anything that you would like to add regarding this topic that I have been interviewing you on?

Do you have any questions that you would like to ask about my research or about me?

Maintaining Rapport:

Thank you for making time to participate in this interview and staying up for the whole duration. Your information is valued and will help me complete my research

Appendix D: Focus interview guide

<u>**Focus Group Interview with Parents**</u>

Opening

E. Hello, my name is Mxolisi Gwala. Thank you for availing yourself and consenting to take part in this interview for my research study.

F. The research is about Exploring the Lived Experiences of Parents of Children with Cognitive Learning Barriers in this place (uMkhambathini). As a parent that is concerned in this research topic, I like to ask you a few questions that are based on your experience about caring for a child who have this learning barrier and attending in mainstream school.

G. Your contribution is very important and will be solemnly used for the purpose of completing this research as part of my Master's degree. I also hope that the discovery of such knowledge will help this community for better changes in the future.

H. This interview may take up 30 minutes of your time; do you agree to stay for this duration?

I will begin by asking your name although you are allowed to use any pseudonym if you wish to withhold your real name.

Name (Pseudonym):

Body

Interview Questions:

17. Do you have a child who has a cognitive learning barrier who attends in this school?
_____
_____
_____
_____

18. Is your child a boy or a girl child?

_____
_____
_____
_____

19. How old is your child and when did you first notice that your child has a cognitive learning challenge?

_____
_____
_____
_____

20. What is the name of the school where your child attends?

_____
_____
_____
_____

21. Why did you consider sending him/her to this school?

_____
_____
_____
_____

22. What challenges does he/she face in his/her learning in the school where he/she attends?

_____
_____
_____
_____

23. What type of a family structure was your child born into, was he/she born in within nuclear/marriage/single parent/ extended family or raised by the relatives?

_____
_____
_____
_____

24. What personal experiences that you have on daily basis that you can share regarding the condition of your child?

_____
_____
_____
_____

25. What personal interventions/ways have you taken/tried to help you cope with the daily challenges that you face as a result of your child's learning barrier?

_____
_____

_26._ What do you do on daily basis to help the learning progress of your child both at home and in the school where he/she attends?

_____
_____
_____
_____

27. Is there any help that you receive from any of your communal institutions such as your church or your extended family?

_____
_____
_____
_____

28. What pressures/challenges do you face in your community due to your child's learning barrier?

_____
_____
_____
_____

29. What personal measures do you take to deal with the pressure/challenges you face due to your child's learning barrier, and do you go about trying to protect your child and yourself from such pressures/challenges from the society?

_____
_____
_____
_____

30. What formal interventions have you taken/do you take to help your child progress despite the condition he/she has and what type of change do you wish to see in the future?

_____
_____
_____
_____

31. What is your opinion regarding education in this place, especially with regards to the condition of your child?

_____
_____
_____
_____

32. What intervention can you mention and desire to see that would help all learners with cognitive learning barriers on their education in this place?

_____
_____
_____
_____

Closing

Is there anything that you would like to add regarding this topic that I have been interviewing you on?

Do you have any questions that you would like to ask about my research or about me?

Maintaining Rapport:

Thank you for making time to participate in this interview and staying up for the whole duration. Your information is valued and will help me complete my research

Appendix E: Consent form-IsiZulu version

UKZN HUMANITIES AND SOCIAL SCIENCES
Consent form for participation in the study/

Ikhasi Lemininingwane Kanye Nemvume Yokubamba Iqhaza Kucwaningo

Date: 3ʳᵈ March 2020

Ngiyanibingelela Bazali

Igama lami ngingu Mxolisi Gwala Umfundi owenza iziqu ze-Masters kwi-Anthropology ngaphansi kwesikole seSayensi yezenhlalakahle Enyuvesi yaKwaZulu-Natali.
Imininingwane yami:

Cell: 074 290 4114/067 081 7716
E-mail: professorblackmale@gmail.com
            214540947@stu.ukzn.ac.za

Lolucwaningo ngilwenza ngaphansi kwesandla sika Dr Balungile Zondi ongumphathi wami ekubhekeleleni inqubo yalolucwaningo. Inininingwane yakhe imi kanje:

Cell: 071 606 5062
E-mail: zondil4@ukzn.ac.za

Umenywa ukuba ube yingxenye noma ubambe iqhaza kulolu cwaningo olumayelana nokuqoqwa kwemizwa yabazali babafundi/babantwana abangaphumeleli noma abavaleleka ngaphandle ngenxa yesimo sontwana sokuphazamiseka ngokomqondo okuba nomthelela ekufundeni kwakhe ezikoleni zikahulumeni ezejwayelekile ezisendaweni yasemakhaya emabangeni aphansi. Inhloso nesizathu saloluacwaningo ukuzwa izimvo nokuphatheka kwabazali emphakathini ngenxa yalesi simo sokungaphumeleli kwabantwana babo, ikakhulukazi njengoba izikole ezibhekelelana nalezi zidingo zokukhubazeka zintulekile emphakathini waseMkhambathini, nokugcina sekuholela abazali ekutheni bathumele abantwana babo ezikoleni ezejwayelekile. Ngalokhu-ke ucwaningo luzama ukunxenxa izishayamthetho ukuba zibone isidingo sokuthi kwakhiwe izikole eziyisipesheli futhi ezisezingeni ezizolekelela kulezi zidingo zabantwana ukuze kwehle umthwalo noma usizi kubazali lokungamukeleki kwabantwana babo emphakathini. Lolucwaningo lubona kubalulekile ukuqoqa lezi zimvo noma ukuphatheka kwabazali okuza nokufunda kwabantwana babo ezikoleni ezejwayelekile bese bengaphumeleli ngenxa yokuntuleka kosizo oluzobhekelana nesimo somntwana ekubeni nalezi zikole eziyisipesheli ziyindlala emphakathini.

Noma lolucwaningo luthinta isihloko esingelula neze ukukhuluma ngaso ngoba sithinta kakhulu imizwa nezinhliziyo zabazali okungenzeka kuvuse iminjunju nemicabango ejulile engemihle, kodwa-ke inhloso yaloluacwaningo akusiyona leyo eqonde ukuthikamezwa kwemizwa nemicabango yabazali, kodwa luhlose ukulalela imizwa yabazali ngezimo abahlangabezana nazo ngenxa yokungaphumeleli kwabantwana babo abaphila nokuphazamiseka kwemiqondo ezikoleni zikahulumeni ezejwayelekile ekubeni nezikole eziyisipesheli ezingabasiza zintulekile emphakathini waseMkhambathini. Lolucwaningo lunethemba lokuthi ukuzwakala kwemizwa yabazali ngalesi simo esiyingwiji ngemfundo yabantwana babo kungaholela ekutheni izishayamthetho zemfundo zilusukumele loludaba lokungaphumeleli noma ukuvaleleka ngaphandle kwabantwana abathintekayo kulolucwaningo, ngokuthi kwakhiwe imithetho emisha noma kulungiswe leyo ekhona emihleni ezayo, yize kungezoba khona isisombululo esiyisipesheli noma inzuzo ngokubamba iqhaza kulolucwaningo.

Lolucwaningo luhlolisisiwe kabanzi futhi luphasiswe yithimba elibhekelela izimiso zokuhle enyuvesi i-UKZN Humanities and Social Sciences Research Ethics Committee (inombolo eqinisekisayo_____).

Ezikhathini lapho kubonakala khona izinkinga noma ukungacaci abazali bangadlulisa lezo zikhalo noma imibuzo ngokuxhumana nami ocingweni ku-0670817716/0742904114 noma nge E-mail professorblackmale@gmail.com noma 214540947@stu.ukzn.ac.za noma bangaxhumana nenyuvesi ngalemininingwane elandelayo ethi: UKZN Humanities & Social Sciences Research Ethics Committee.

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private   Bag   X   54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

Ukubamba iqhaza kulolucwaningo kuzoba ngemvume yabazali, hhayi ngempoqo. Abazali bavumelekile ukubuza imibuzo lapho kuzoba nesidingo khona futhi bavumelekile ukweqa imibuzo ababuzwa yona noma ukuhonxa kulolucwaningo lapho befisa khona ngezimo zokungakhululeki. Lokhu kuzokwenzeka ngale kokuhlawuliswa noma ukunqabelwa ukuba yingxenye yenzuzo engenziwa yiloluncwaningo. Impumelelo yalolucwaningo incike kakhulu kulwazi nemininingwane eyaziwa noma ebonwa abazali, lokhu kusho ukuthi lolucwaningo lungathikamezeka ekutheni luthole ulwazi olwanele olungasiza umphakathi wonkana ukuthi uletheIwe izinguquko uma umzali noma abazali bekhetha ukungazibandakanyi nhlobo noma ukuhoxa kulolucwaningo ngokuthi izinkinga ezibhekana nabazali ngenxa yokuntuleka kwezikole eziyisipesheli emphakathini esemakhaya ngeke zaziwe noma zifinyelele ezindlebeni zeziphathimandla zemfundo.

Kulindelekile ukuba abazali noma umzali obambe iqhaza kulolucwaningo azithole esesimweni sokungakhululeki noma kuvuke imizwa engemihle yize lokhu kungeyona inhloso yalolucwaningo. Abazali bayaziswa ukuthi umbuthi wolwazi uyazwelana nabo mayelana nalesi simo esithinta abantwana babo.

Ulwazi oluzokolekwa noma olukolekiwe luzogcineka luyimfihlo phakathi kwabazali noma umzali nomqoqi wolwazi futhi luzosetshenziswa ngokuhlobene nocwaningo kuphela. Abazali bazocelwa ukuba basayinde ngamunye imvume yokuqoshwa kwamazwi abo lapho kudingeka khona.

Imvume

Mina…………………………………… (igama lomzali) ngazisiwe ngoncwaningo olumayelana nokukolekwa kwemizwa yabazali babantwana abangaphumeleli noma abavaleleka ngaphandle ezikoleni zikahulumeni ezejwayelekile ngenxa yesimo somntwana sokuphazamiseka ngokomqondo wumkoleki wolwazi uMxolisi Gwala.

Ngiyayiqonda inhloso nenqubo yalolucwaningo oluthinta imizwa yami ngesimo esibhekene nesimo sontwana wami.

Nginikeziwe ithuba lokuthi ngiphendule imibuzo mayelana nalolucwaningo futhi ngiphendule ngendlela engigculisayo.

Ngiyaqinisekisa ukuthi ukubamba kwami iqhaza kulolucwaningo kungemvumo yami futhi ngazisiwe ukuthi ngingahoxa kulolucwaningo noma kunini ngale kokuhlawuliswa noma ukuthinteka kwamalungelo ami.

Ngazisiwe ngobungozi obungalandela noma imizwa engavuka ngenxa yokuzibandakanya kwami kulolucwaningo.

Lapho nginemibuzo noma ukukhathazeka khona mayelana nalolucwaningo ngiyazi ukuthi ngingaxhumana nomkoleki wolwazi ngalezi zindlela zokuxhumana

Ucingo: 0742904114/067 081 7716
Noma nge E-mail: professorblackmale@gmail.com noma 214540947@stu.ukzn.ac.za

Ngiyazi ukuthi uma kwenzeka ngiba nemibuzo noma ukukhathazeka ngamalungelo ami ngokubamba iqhaza kulolucwaningo noma enye ingxenye ethinta lolucwaningo noma umkoleki wolwazi uqobo ngingaxhumana nethimba lenyuvesi elibhekelela izimiso zokuhle kulemininingwane elandelayo:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private   Bag   X   54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557 - Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

Ngiyavuma ukubamba iqhaza kulolucwaningo

_____   _____
Sayinda (umzali)   Usuku

_____   _____
Sayinda (ufakazi)   Usuku
(Uma ekhona)

_____   _____

Sayinda (utolika)   Date
(Uma ekhona)

Appendix F: Consent form-English version

UKZN HUMANITIES AND SOCIAL SCIENCES

Consent form for participation in the study/

Information Sheet and Consent to Participate in Research

Date: 3rd March 2020

Hello

My name is Mxolisi Gwala. I am a Masters student at the University of KwaZulu-Natal from the school of social science in the discipline of Anthropology. I can be contacted as follows:

Cell number: 071 580 1350/0742904114

E-mail: professorblackmale@gmail.com or

214540947@stu.ukzn.ac.za

I am also conducting this research study under the supervision of Dr Balungile Zondi, she oversees my continuing writing of this research. She can be contacted for any questions and concerns regarding this research as follows:

Cell: 071 606 5062

E-mail: zondil4@ukzn.ac.za

You are being invited to consider participating in a study that is about exploring the lived experiences of parents of children with cognitive learning barriers at uMkhambathini. The aim and purpose of this research is to collect personal experiences of parents whose children have cognitive learning barriers and are attending in mainstream schools. The study is interested in learning about parents daily experiences especially because these children are either excluded or do not progress in mainstream schools while there are no alternative special schools in the rural area (Mkhambathini) that can cater for their learning needs. The study is expected to sample a total of fifteen (15) parents from the three schools to participate in the study. The collection of data will be done at the three schools where parents of affected children are known, having obtained permission to do so. Data will be collected from two sessions from parents through the usage of personal interviews with each parent and guided focus groups involving all (5) parents/participants who volunteered to participate from each school.

The study does not include or aim to cause any risk, however, should there be any unforeseen distresses the participants will be advised to discontinue the process or skip the questions that they would feel they are not comfortable with. This will be advised prior to the completion of the research process. However, the study is hopeful that such exploration of everyday lived

experiences of parents may motivate an effort from the public policy making to realize the implementation of adequate special schools in the rural place or provision of adequate inclusive support in order to curb the exclusion and regression of learners living with disability in the rural place such as in Mkhambathini, although participation in this research study might not provide direct benefits to the participants nor provide an immediate response to the challenges. Participation in this study will be solely voluntary and all participants will be treated fairly while allowed to withdraw from the study in case of discomfort. The study will also communicate the role of inclusive education as implemented within their communities which will be meant to help parents understand what should be benefitted by their children through this educational policy.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (approval number_____).

In the event of any problems or concerns/questions you may contact the researcher at:

Cell number: 0715801350/0742904114

E-mail: professorblackmale@gmail.com

      214540947@stu.ukzn.ac.za

 or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private   Bag   X   54001
Durban
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Participants are being assured that participation in this research is voluntary and may withdraw participation at any point should they wish to. In the event of refusal/withdrawal of participation the participants will not incur penalty. The participants will not even be persuaded to continue with the research process where they have expressed their will to discontinue with the research process but this will only be listed as part of limitations encountered by the researcher during the research process. Participants are advised to inform the researcher of their withdrawal of consent from study participation.

The study does not aim to cause any harmful cost to the participants, the participants will asked to communicate their thought on the questions that will be posed to them and their identities will be protected. The study will try by all necessary means to avoid any cause of emotional distress by asking participants to communicate their discomforts or withdrawal. I will liaise with my supervisor and the university to assist me with psycho-social support to participants should they show any indication of being in emotionally distress during data collection or should this prove to be one of my research experiences.

The study aims to protect confidentiality of information through non-disclosure but only will be used for research completion purposes and will be kept as research evidence or proof when required so. The participants will be advised to consent separately for audio recording where necessarily needed such as in the focus groups

----

Consent to Participate in the Study

I………………………………………………….have been informed about the study entitled (Exploring the Lived Experiences of Parents of Children with Cognitive learning barriers at uMkhambathini). The case study of three primary schools in Mkhambathini, Pietermaritzburg) conducted by Mxolisi Gwala of the University of KwaZulu-Natal.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at:

Cell: 074 290 4114/071 580 1350

E-mail: professorblackmale@gmail.com

214540947@stu.ukzn.ac.za

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

I hereby provide consent to

Audio-record my interview / focus group discussion   YES /NO

_____   _____

Signature of Participant   Date

_____   _____

Signature of Witness   Date

(Where applicable)

_____   _____

Signature of Translator   Date

(Where applicable)

………

UKZN HUMANITIES AND SOCIAL SCIENCES

Consent to participation in a recorded focus group between parents and the researcher/

Consent to Audio Recording

I………………………………………………………….have been informed about the study entitled (Exploring the Lived Experiences of Parents of Children with Cognitive learning barriers at uMkhambathini). The case study of three primary schools in Mkhambathini, Pietermaritzburg) conducted by Mxolisi Gwala of the University of KwaZulu-Natal.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at:

Cell: 074 290 4114/071 580 1350

E-mail: professorblackmale@gmail.com

214540947@stu.ukzn.ac.za

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001
Durban
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

I hereby provide consent to

Audio-record my participation / YES /NO

_____   _____

Signature of Participant   Date

_____   _____

Signature of Witness   Date

(Where applicable)

_____   _____

Signature of Translator   Date

(Where applicable)