

**EXPERIENCES OF MOTHERS OF CHILDREN WITH SEVERE INTELLECTUAL  
DISABILITY REGARDING PARTNER SUPPORT IN THE CAPRICORN DISTRICT,  
LIMPOPO PROVINCE**

by

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## DECLARATION

I declare that the dissertation, "Experiences of mothers of children with severe intellectual disability regarding partner support in the Capricorn District Limpopo Province," hereby submitted to the University of Limpopo, for the degree of Master of Nursing Science has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.



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**Makgoga, MT (Mr)**

**21 DECEMBER 2022**

**Date**

## **DEDICATION**

This study is dedicated to my late brother Mahubane William Makgoga (Hlabirwa).

## ACKNOWLEDGEMENTS

I thank God for his blessings in my life and grace through this study.

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## ABSTRACT

**Background:** Raising a child with a severe intellectual disability is a challenge for most mothers, as most mothers experience a lack of support from their partners. This lack of partner support causes high stress and marital problems for mothers.

**Purpose:** The purpose of the study was to determine the experiences of mothers of children with a severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province.

**Study method:** A qualitative, explorative, and descriptive design was applied to explore and describe the experiences of mothers of children with a severe intellectual disability regarding partner support. Participants were selected using a purposive sampling method. Data were collected from twelve mothers of children with severe intellectual disability using a semi-structured interview guide. Data were analysed using Tesch's approach to data analysis. Trustworthiness was ensured by using four criteria of trustworthiness, credibility, dependability, confirmability, and transferability. Ethical clearance was obtained from the Turfloop Research Ethics Committee (TREC) and permission to collect data was granted by the Department of Education Limpopo Province and the principals of the selected special schools. The details of the study were explained to the participants who then agreed to participate in the study by signing a consent form.

**Results:** The findings of the study showed that mothers experienced negative and positive partner support. The positive supports include caring about and loving the child, having a positive relationship with the child, and having instrumental support through sharing supervision and caring. The most negative support was partners not accepting the child, partners lacking emotional support and marital relationship challenges.

**Limitation:** Data was collected during the COVID-19 lockdown, which delayed getting permission to collect data as the schools were closed for a long time.

**Conclusion:** The healthcare practitioners as the first people to identify the disability, should immediately inform the mothers and their partners about the child's disability and start with counselling immediately and continue with counselling throughout the

development. The recommendation of the study focused on the promotion of partner support through research, education and training

**KEYWORDS:** experiences, mothers, children, severe intellectual disability, partner, support

## **DEFINITION OF CONCEPTS**

### **Child**

A child refers to a young human being who is not yet an adult (Hornby, 2010). In this study, a child (plural children) refers to human beings under eighteen years old who have a Severe Intellectual Disability (SID) in Capricorn District Limpopo Province.

### **Experience**

Experience refers to something personally encountered, undergone, or lived through (Merriam-Webster Incorporated, 2015). In this study, experience refers to the day-to-day partner support lived through by mothers of children with severe intellectual disability in the Capricorn District, Limpopo Province.

### **Mother**

A mother refers to the female parent of children (Hornby, 2010). In this study, a mother (singular) refers to a woman who is about a child with a severe intellectual disability, to whom she has given birth in the Capricorn District, Limpopo Province.

### **Partner**

A partner refers to someone who is closely involved with in some way (Mcintosh, 2013). In this study, the partner refers to a mother's companion having a child with a severe intellectual disability.

### **Support**

Support refers to the sympathy and helps that one gives another in a difficult situation (Hornby, 2010). In this study, support refers to the help mothers of children with severe intellectual disabilities will get from their partners.

### **Severe intellectual disability**

Severe intellectual disability refers to deficits in general intellectual functioning and adaptive functioning (Townsend, 2012). In this study, severe intellectual disability refers to the intellectual conditions that the children in Capricorn District Limpopo Province are suffering from.

## LIST OF ABBREVIATIONS

<b>CD</b>	Capricorn District
<b>DOH</b>	Department of Health
<b>ID</b>	Intellectual Disability
<b>LP</b>	Limpopo Province
<b>PLK</b>	Polokwane
<b>PM</b>	Polokwane Municipality
<b>SID</b>	Severe Intellectual Disability
<b>SA</b>	South Africa
<b>SASSA</b>	South African Social Security Agency
<b>TREC</b>	Turfloop Research Ethics Committee
<b>USA</b>	United State of America



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## CHAPTER 1

### OVERVIEW OF THE STUDY

#### 1.1 INTRODUCTION AND BACKGROUND

The mothers of children with Severe Intellectual Disability (SID) face many challenging situations that compel extra support from their partners to help them raise their children (Aldosari & Pufpaff, 2014). Partner support plays a critical role in the mental health outcome of mothers and the well-being of their children (Davey-Rothwell, Stewart, Vadnais, Braxton & Latkin, 2018). Moreover, partner support was found to relieve the effect of stress and served as a protective factor against stress, especially, for mothers raising a child with a severe intellectual disability (Mohan & Kulkarni, 2018). The study conducted in Saudi Arabia by Aldosari and Pufpaff (2014) agrees that support from partners is significant in reducing the stress experienced by mothers of children with SID.

The prevalence rate of SID is estimated at 1% to 3% of the global population (Oti-Boadi, 2017). South Africa (SA) is among the countries faced with the problem of a growing prevalence of intellectual disability (Phillips & Numbissi, 2011). It is estimated that in SA about two million people are living with some kind of disability; out of this number, over 200 000 South Africans have been identified as having SID (Adnams, 2010). The study conducted by Sumbane (2021) in the Limpopo province, South Africa, found that mothers of children with intellectual disabilities experience a lack of partner support. Fathers were found to be uninvolved in raising their own children, and some even refused to accompany the mother and their children with SID to the hospital for follow-up care. Mothers were found to be blamed for having children with SID. These might be the cause of a high level of stress and mental problems experienced by mothers raising children with SID compared to mothers without SID (Jess, Totsika & Hastings, 2018). Raising a child with (SID) is a challenge for most mothers (Thwala, Ntinda & Hlanze, 2015).

A qualitative exploration study conducted in India by Vadivelan, Sekar, Sruthi, & Gopichandran (2020) also revealed that mothers of children with SID experience a lack of support from their husbands and family in the process of caregiving.

The mothers reported suffering the ill effects of alcoholism and domestic violence from their husbands. Compromise on the care provided to the other family members and their children without SID. There are feelings of aches and pains due to the heavy physical activity of caregiving and guilt about the child's condition. Financial burdens due to the difficulty in balancing family and work. Similarly, the study conducted in the United State of America (USA) by Hartley, DaWalt and Schultz (2017) reported that parents of children with SID report less time with a partner, lower partner closeness and fewer positive couple interactions than a parent without children with SID. Furthermore, the mothers' highlight that having a child with SID can strain a marriage. The study conducted by Overall, Fletcher and Simpson (2010) in New Zealand, found that people who reported greater goal support from their partners evaluated their relationships more positively. This support component was most related to relationship satisfaction.

Fathers of children with SID in Sweden were found to be less involved in caring of their children with SID, unlike mothers. Fathers reported continuing their paid work while mothers increased their involvement in caring for their children. Furthermore, fathers focus more on the outside world while mothers pay closer attention to the day-to-day care of their SID children and their family (Bostrom & Broberg, 2014). Mothers of children with SID were in single parents' households as their partners were no longer in contact with them, providing little physical and emotional support (Jessica & Rhodes, 2018).

The results of the study conducted in Ghana differ from the above-mentioned studies because about seventy percent of mothers of children with SID reported receiving support from their partners, which assisted them in sustaining their mental health. Three percent of mothers reported that their partner helped a lot because when mothers were unable to take their children with SID to school, they took their children to school, and even at home, they help with taking care of their children (Oti-Boadi, 2017). In China, fathers of children with SID are sometimes found to have a positive response toward their child's diagnosis and become empowered and stronger. This helps them to support their partners in the care of their child (Hu, 2022). Children with SID may have positive effects on



their parents despite the huge responsibility for childcare and household duties those parents face (Bostrom & Broberg, 2014).

According to the Mental Health Care Act No 17 of 2002, children with SID are incapable of making informed decisions due to their mental health status, as a result, they require assisted care, treatment, and rehabilitation. Therefore, support from the parents, family members, community, and health professionals and educators is important for their wellbeing.

Given the above background, the researcher found that very little is known about the experiences of mothers of children with SID regarding partner support in South Africa and even in Limpopo Province. Mothers also reported to experienced stressful life events, due to lack of partner support. Hence the current study aims to determine mothers' experiences regarding partner support on their children with SID in the Capricorn District Limpopo Province. The researcher found it necessary to conduct this study to understand better the experiences that mothers of children with severe intellectual disabilities encounter in terms of partner support.

## **1.2 PROBLEM STATEMENT**

The researcher observed that mothers who bring their children with severe intellectual disability for psychological assessment at a specific hospital where the researcher was working bring their children alone without their partners. The researcher observed mothers struggling alone, carrying their children with wheelchairs, and carrying bags alone. It seems like mothers of children with severe intellectual disability experiences problems about partner support, as supported by the following studies: Budak, Kucuk and Civelek (2018) found that mothers when they learned the diagnosis of their children, their partners had more difficulties in accepting the situation than mothers, this result in the partners not providing sufficient support for the care of their children with SID. A study conducted in Uganda and Kenya by Rohwerder (2018), reported that intellectual disability is usually placed on the mother's side of the family rather than the father's side. Some believed that the disability of children is because of the sin

of their mothers. As a result, partners blame the mothers instead of supporting each other.

The study by Sumbane (2021) also recommended that a study on partner support be conducted in the Limpopo Province to understand better the challenges that mothers of children with severe intellectual disabilities encounter. In addition, the most concerning finding in the study conducted by Williams (2019) was that professionals are excluding fathers of children with intellectual disabilities, which is an area of practice that needs to be urgently addressed.

Against this background, the researcher was motivated to determine the experiences of mothers of children with a severe intellectual disability regarding partner support to improve on the support provided to both mothers.

### **1.3 PURPOSE OF THE STUDY**

The purpose of the study was to determine the experiences of mothers of children with a severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province.

### **1.4 THE OBJECTIVE OF THIS STUDY**

The objectives of this study were:

- To explore mothers' experiences of children with severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province.
- To describe mothers' experiences of children with severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province.
- To recommend measures to promote partner support to the parents of children with severe intellectual disability.

### **1.5 RESEARCH QUESTION**

What are mothers' experiences of children with a severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province?

## **1.6 THE THEORETICAL FRAMEWORK**

The theory is a set of interrelated concepts, definitions, and propositions that present a systematic view of phenomena to explain and make predictions about those phenomena (LoBiondo-Wood & Haber, 2014). According to Brink, Van der Walt, and Van Rensburg (2014), a theoretical framework is a study framework based on propositional statements from a theory of theories. This study was guided by Lakey and Cohen theory (1984) of social support and measurement. Social support and measurement theory has three major concepts: the stress and coping perspective, the social constructionist perspective, and the relationship perspective (Lakey & Cohen, 2000).

### **1.6.1 The stress and coping perspective**

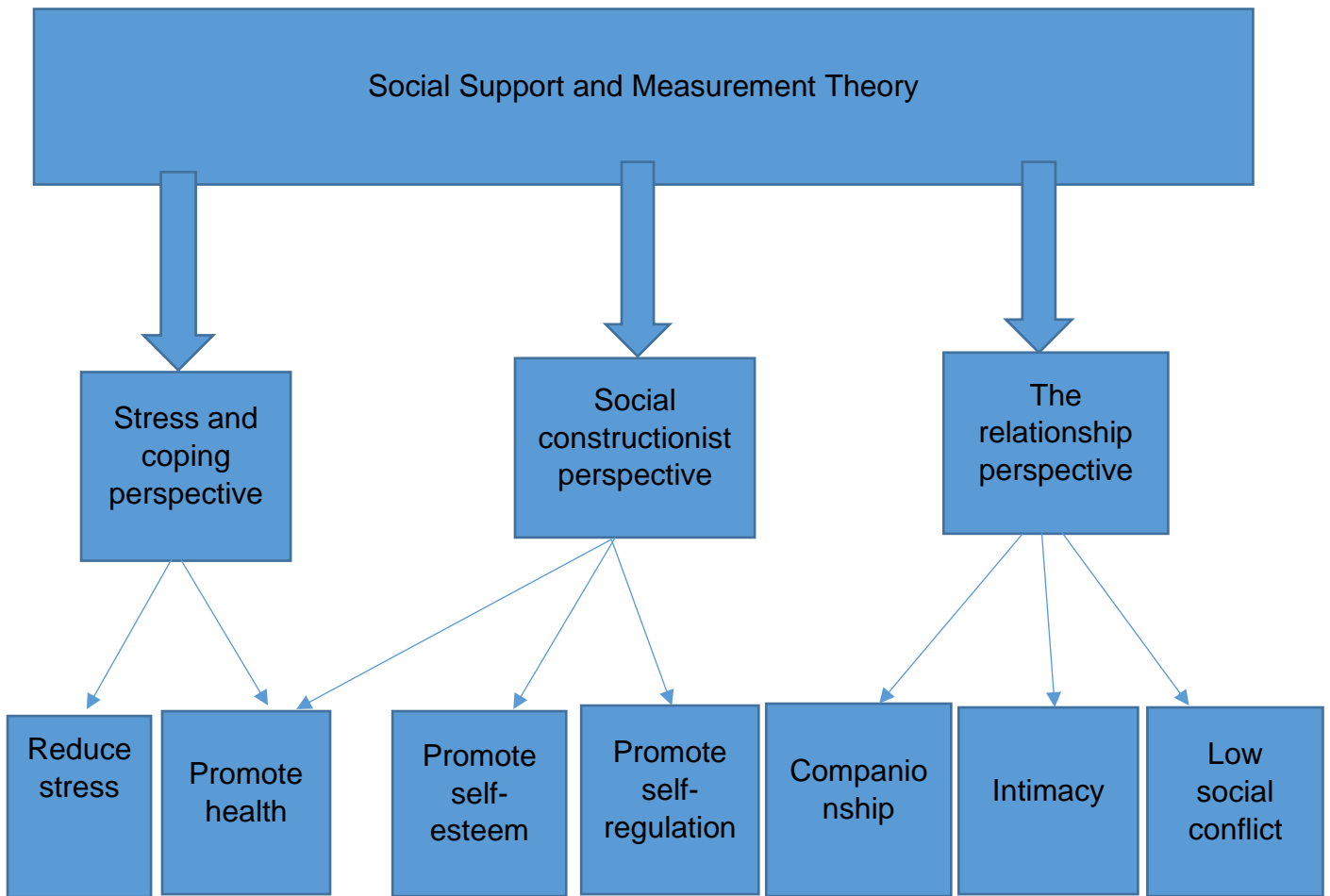
The stress and coping perspective propose that support contributes to health by protecting people from the adverse effects of stress. The stress and coping perspective states that social support reduces the effects of stressful life events through either the support actions of others or the belief that support is available (Lakey & Cohen, 2000). In this study, stress refers to the challenges experienced by mothers of children with SID regarding partner support. While coping perspective in this study refers to the support that the mothers of children with SID, believe they got from their partners. Thus, to promote their health and reduce stress, as indicated in Figure 1.1.

### **1.6.2 The social constructionist perspective**

The social constructionist perspective proposes that support directly influences health by promoting self-esteem and self-regulation, regardless of the present stress. The social constructionist perspective predicts that the self and social world, including social support, are inextricably (Lakey & Cohen, 2000). In this study, the social constructionist perspective refers to informal support that mothers of children with SID should receive from their partners to promote health, self-esteem, and self-regulation. Self-esteem in this study refers to the confidence that the mothers of children with SID have towards their partners regarding the support they get from them. Self-regulation in this study refers to the behaviour that mothers of children with SID display towards their partners regarding the support they get from them, see Figure 1.1.

### **1.6.3 The relationship perspective**

The relationship perspective predicts that the health effects of social support cannot be separated from relationship processes that often co-occur with support such as companionship, intimacy and low social conflict. While companionship involves shared leisure time and other activities that are undertaken primarily for the intrinsic goal of enjoyment. Relationship satisfaction is a global, subjective evaluation of a relationship and intimacy is the bound, connected, and close feelings people have towards each other. Social conflict includes criticism, breaking promises, or fighting for limited resources (Lakey & Cohen, 2000). In this study the relationship perspective refers to when mothers of children with SID receive support from their partners, both partners will feel connected, have close feelings towards each other and will experience low social conflict, as illustrated in Figure 1.1.



**Figure 1.1: Brain Lakey and Sheldon Cohen theory of social support and measurement theory (Lakey & Cohen, 2000)**

### 1.7 SUMMARY OF RESEARCH METHODOLOGY

Qualitative explorative and descriptive design was applied in conducting this study. The qualitative research approach is a systematic, subjective approach used to describe life experiences and give them meaning (Grove, Gray & Burns, 2015). The explorative design allowed the researcher to explore the experiences of mothers of children with SID regarding partner support.

The study was conducted at the three selected special schools in the Capricorn District of the Limpopo Province using mothers of children with SID as participants. A non-probability purposive sampling technique was used to obtain twelve mothers of children with SID at three selected special schools as participants. Data were collected using a semi-structured interview. The 8 steps

of Tesch's open coding method, as described by Beck and Polit (2014) were used to analyse the transcribed data. More details on the research methodology will be discussed in Chapter 3.

In this study, trustworthiness was ensured by using 4 criteria: credibility, dependability, confirmability, and transferability (Brink et al, 2014). The 4 criteria of trustworthiness will be discussed in full in Chapter 3 of this study.

Ethics are standards or patterns of behaviour that direct moral choices about the use and relations with others (Cooper & Schindler, 2011). The following ethical standard was adhered to while conducting the study. Ethical clearance, permission to conduct the study, informed consent, the principle of confidentiality, the principle of privacy, the principle of anonymity, the principle of respect for a person, the principle of justice and the principle of non-maleficence. More details of ethical considerations will be discussed in Chapter 3 of this study.

Therefore, to prevent bias, purposive sampling and bracketing were used to sample the study population. Thus, to prevent bias the language spoken and understood by the participants was used to interview to ensure that all participants understood and could express their views and ideas. Bias will be discussed in Chapter 3 of this study.

## **1.8 SIGNIFICANCE OF THE STUDY**

### **To mothers of children with SID**

- The findings of the study might help the mothers of children with SID to get full support from their partners
- The study's findings will assist the mothers with the coping mechanism regarding partners in the care of their children with SID.
- Partners support to mothers of children with SID will aid mothers in sustaining their mental health by reducing their stress levels in the care of their children

### **To fathers of children with SID**

- The published findings of the study will help out fathers to learn to leave, take care and manage their children with SID.

- The findings of the study might empower fathers of children with SID with knowledge regarding the condition of their children so that they can be able to assist and support their partners (mothers) in their care of their children.

#### **To severe intellectual disability children**

- The findings of the study will help children living with SID get full support from both parents' mothers and father figures (partners) and help them be fully cared for.
- The study's findings will allow children living with SID to be supported emotionally and physically and to be loved by their parents.

#### **To Community**

- The study's findings may educate the community on how to leave with partners of children with SID and how to provide support to them and their children with SID at the community level.
- The findings of the study will teach the community to stop stigmatising and abusing partners of children with SID but rather assist and support them by involving them in the services within the community.

#### **To the Department of Health and Department of Education**

- The study findings might assist the Department of Health (DOH) and the Department of Education to develop special strategies and guidelines regarding partner support for children with SID.
- The study's findings may encourage the DOH to do monthly campaigns to educate partners (fathers) about the support they should give their partners (mothers) on their children with SID.
- Through the study findings, the Department of Education will add in-service training on partner support with a child with a SID at their monthly parents' meeting.

## **1.9 ORGANISATION OF THE STUDY**

### **Chapter 1: Overview of the study**

**Chapter 2:** Literature review

**Chapter 3:** Research design and methods

**Chapter 4:** Results and discussion of the findings

**Chapter 5:** Summary, limitations, recommendations and conclusion

## **1.10 CONCLUSION**

Chapter 1 has provided an introduction and background, the objective of the study, the research question, a summary of the research methodology, measures to ensure trustworthiness, bias, the significance of the study and ethical considerations. The next chapter will focus on the literature review



## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

Chapter one of this study discussed the overview of the study. Moreover, chapter two focuses on the literature review. The literature review is a critical evaluation of a subject used for research purposes, policy, practice development and critical analysis of theoretical and conceptual frameworks (Coughlan, Cronin & Ryan, 2013). The literature review provides the researcher with the current theoretical and scientific knowledge about a particular problem, synthesizing what is known and not known (Burns & Grove, 2011). The study focused on what is already known worldwide, Africa, Sub-Sahara, and South Africa (SA) based on the research and their findings regarding partner support for mothers of children with SID.

A thematic literature review was used to search the literature. An extensive search of the literature was conducted from March 2011 to 2021 using four electronic databases: EBSCOhost, Science direct, World cat, and Google Scholar with the help of the library information specialist.

The search terms for the literature used were: “partner support, spouse support, experiences of mothers of children with SID, the prevalence of SID”. Thus, the articles were included if they explored partner or spousal support, severe intellectual disability, and the prevalence of SID in both qualitative and quantitative studies. Therefore, the articles excluded were those published before 2005 and did not address the experiences of mothers of children with a severe intellectual disability regarding partner support.

#### *The concept of “Intellectual disabilities”*

Intellectual Disabilities (ID) are classified according to severity into four categories that are, mild, moderate, severe, and profound. Each classification comes up with its degree of intellectual, physical, and adaptive functioning and will require a special level of support and care (American Psychiatric Association,

2013). This study focused on the support their partners provided to the mother of children with SID.

## **2.2 PARTNER SUPPORT FOR A CHILD WITH SID**

Donato, Lafrate, Bertoni and Rapeli (2020) defined partner support as the process of responding with helping acts behavioural as well as psychological to a difficult or problem of one's partner in a couple of relationships. A study done in the United State of America by Machalicek, Lang and Raulston (2015) stated that education and support programmes and interventions, and strategies regarding partner support are needed to assist partners in facilitating and nurturing their children with SID. The findings of Thwala, Ntida and Hlanze (2015) in Swaziland, suggested that there is a need to develop training programmes which will empower partners to support with knowledge regarding the care of their children with SID and again to partner with educators for the benefit of their children with SID.

According to Budak, Kucuk and Civelek (2018) in their study of life experiences of mothers of children with an intellectual disability: A qualitative study in Turkey stated that the relationship between the partners as showed both positive and negative progress. Some mothers in the study done by Carpenter and Egerson (2009) said that when asking their partners to take care of their children with SID, their partners always blame the mothers for giving birth to children with SID while other mothers expressed experiencing partners support in the care of their children with SID, two of the mothers stated that they never argue with their partners instate the partners understood and supported each other and did not blame each other in their life struggle. Other mothers reported that rather than causing arguments the diagnosis leads to more positive interaction with their partners (Budak, Kucuk & Civelek (2018).

Davys, Mitchell and Martin (2016) in their study on fathers of people with intellectual disability: a review of literature in Manchester, found that some fathers were involved in the day care of their children as they worry about their children with SID and want the best for them, and they took the main carer roles in their family to look after their children. The above study was supported by the study done in Stellenbosch by Elna and Abraham (2020) on resilience

characteristics of families with children with severe or profound intellectual disability, argued that support from within the family unit was deemed important by all the participating families as mothers of children with SID mentioned family members, their partners who played a valuable role in family's adaptation process in accepting the child. The study done in Stellenbosch by Durr and Greeff (2020) indicated that support from within the family unit by partners and extended family was important for both partners as partners had time to rest. The Study done by Purba and Simanjuntak (2020) on father's acceptance and rejection of children with disabilities differ from the above study as the study argued that initially there was a rejection of children with SID by their partners because they were ashamed of having children with SID and mothers took the role of parenting without the support of their partners, partners who didn't accept their children born with SID were harbour latent anger towards their children with SID so that the care became the mother's own without the partner participating in parenting.

### **2.3 MARITAL CHALLENGES FOR PARTNERS OF CHILDREN WITH SID**

Jackson, Steward, Roper and Muruthi (2018) stated that marital relations are often affected following the birth of a child with SID as partners have to acquire information about the intellectual and developmental disabilities, address unique medical needs and manage the complex needs of children with SID. Mothers of children with SID reported that through the child's development, their partners develop a feeling of sadness, anger, frustration, guilt, helplessness, and loneliness as they are faced with ongoing stressors associated with caring for their child with SID.

Jessica and Rhode (2018) agree with the study stating that mothers of children with SID in Australia reported that their marriage was under significant relational stress. Other mothers felt there was little time to focus on their marriage but on the needs of children with SID. Similarly, mothers of children with SID in the United State of America reported having a challenge of an increased number of divorces by partners as compared to mothers without SID children as mothers of children with SID take much of time looking after children with SID than partners (Hartley, Seltzer, Barker & Greenberg, 2011).

## **2.4 FINANCIAL CHALLENGES FOR PARTNERS OF CHILDREN WITH SID**

A study done by Jung-Hwa, Greenberg and Seltzer (2011) on parenting a child with a disability in the United State of America, argued that caring for a child with SID brings multiple challenges to mothers, such as additional financial burden for treating their child 's condition, dealing with the child 's problematic behaviour. These challenges create a high level of psychological challenge often expressed as depression, anxiety, and somatic symptoms for mothers.

The study done in Ghana by Oti-Boadi (2017) stated that having a child with SID may be associated with personal and financial adjustments and adaptation to the new role of meeting the unique needs of a child. The above study is supported by a study done by Thwala, Ntinda and Hlanza (2015) in the study of lived experiences of parents of children with disability in Swaziland, which found that raising a child with SID is expensive because mothers have to buy medical equipment and supplies such as wheelchairs and have to pay medical care, private education, learning equipment, and specialised transportation.

Amikile and Outwater (2012) stated that mothers of children with SID in the United Kingdom reported economic challenges as their children interfere with various activities such as business and extra expenses associated with their illness, and mothers are no longer able to leave their children to work their focus is on their child. Laderera and Hall (2017) argue that financial hardship is another challenge that partners of children with SID face as partners experience high expenditure than families of children without SID. This was supported by a study done by Lungue, Thwala, Ntinda and Hlanze (2015) stated that the expenses may arise from medical equipment and supplies such as wheelchairs, medical caregiver expenses, private education, learning equipment, tutoring and specialised transportation. Fareo (2015) in his study reported that this additional financial burden to the partner, in the end, leads to neglect as most partners of children with SID cannot cope with these economical demands. Many partners of children with disabilities are economically strained as mothers are not able to return to work and there may be an extra expense in supporting the child (Fareo, 2015).

## **2.5 THE BURDEN OF MOTHERS OF CHILDREN WITH SID WITHOUT PARTNER SUPPORT**

A study was done in Israel by Heimen (2021) on parents' voice: parents' emotional and practical coping with a child with special needs stated that mothers of children with SID experience more parenting stress than mothers of children without SID. Oti-Boadi (2017) in his study exploring the lived experiences of mothers of children with intellectual disability in Ghana, argued that raising children with SID creates enormous psychological challenges often expressed as depression, anxiety, and somatic symptoms for mothers.

Anclair (2017) argues that being a mother of a child who suffers from SID is a major psychological and social challenge. As the challenges have an impact on both the child and the mother's emotional and social functioning. A study done by Anclair (2017) on fears, stress, and burnout in parents of children with chronic conditions stated that the challenge such as stress are likely to arise, and it can be more demanding than the illness itself as the mothers are not only responsible for taking physical care of their child but must also deal with the disease in terms of medical, school-related and another social aspect. The daily care of a child with SID is demanding as the mother has to bath, dress, and feed and nurture the child which can lead to long-term burdens that are stress and fatigue for the mother (Oti-Boadi 2017).

Such beliefs affect the mothers as well as the partner and lead to the exclusion and withdrawal of the child and partners from social life to avoid embarrassing comments and constant reminder of the child's condition (Faroo, 2015). According to Chukwe, Okoye, Onyeneho and Okeibunor (2019) in their study of coping strategies of families of a person with a learning disability in the Lmo state of Nigeria, reported that mothers may feel isolated, lonely and confused due to stigmatization of the community members for having child with SID as their child has less support from the environment in the society neighbour and community members isolate mothers of children with SID due to ignorance and poor definition of SID in the cultural setting. Mothers of children with SID are restricted from participating in activities of everyday life, such as engaging in leisure

activities, as they are being isolated by community members (Abrahansson and Palmberg, 2016). According to Ambikile and Outwater, in 2012 in their study of challenges of caring for children with a mental disorder, experiences and views of caregivers attending the outpatient clinic at Muhimbili national hospital Dares salaam Tanzania find that societal stress may also arise when relatives and neighbours become frightened by the child with SID, and this may lead them to become cruel and distancing themselves from mothers of a child with SID. This may complicate the mother's problem that they may begin to consider themselves abnormal and begin to ask God what they have done to get such a child with SID (Ambikile and Outwater, 2012).

## **2.6 SUPPORT SERVICES FOR PARTNERS OF CHILDREN WITH SID**

According to Carpenter and Egerson (2009) intervention programmes are a necessary part of the process involved in supporting mothers of children with SID. Such intervention requires an active involvement of a wide range of health professionals such as social workers, teachers, psychologists, therapists, medical officer, and nurses. Skills training, partner's education, and advocacy role are required on the part of mothers and professionals. Health professionals should also support partners and advocate for more generous social and financial resources for these partners and this support must come from the community, government, and non-government organisations for the partners to care adequately for their children (Tiger and Makhubele, 2019).

### **2.6.1 Religious support for partners of children with SID**

Pitten (2008) stated that the role of religion in all cultures provides a major source of support for a child with SID as a family, including emotional comfort, strength for the daily task to the diagnosis and hope for the future. A study was done by Dura-Vila and Dein (2010) on children with intellectual disability: A gain not a loss: parental beliefs and family life argue that most partners may use religion as a way to make sense of why SID has happened to their child and to come to an understanding about themselves and their child's disability in a religious framework. The birth may evoke positive attributions such as the child with SID is a gift from God. Pitten (2008) reported that Catholicism the dominant religion in the Latino culture, plays a major role in the acceptance of their children with

SID. Most Latino mothers view their role as similar to that of the virgin mother, one of sacrifices and dedication. Their faith gives them strength, patience and the feeling that God is with them on a daily basis because of God's presence. Latino partners feel less depressed and have the strength in taking care of their children with SID and they have faith that their child's condition will improve (Pitten, 2008).

## **2.7 CONCLUSION**

Chapter two discussed the literature review, partners' support for children with SID, marital challenges for partners of children with SID, financial challenges for partners of children with SID, the burden for mothers of children with SID without partner support, and the support services for partners of children with SID that includes, religious support for the partner of children with SID. The next chapter will focus on the methodology of this study.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

This chapter entails the research methodology in detail. The research approach, the study site, research design, population to be studied, sampling method and sample size, data collection and data analyses. Therefore, the measures taken to ensure trustworthiness and ethical consideration are discussed.

#### **3.2 RESEARCH APPROACH**

According to Burns and Grove (2017), research methodology is defined as the process or plan for conducting the specific steps of the study. In this study, a qualitative research approach was used. The qualitative research approach is a systematic, subjective approach used to describe life experiences and give them meaning (Burns & Grove, 2017). A qualitative research approach was used in this study for the researcher to determine the experiences of mothers of children with severe intellectual disabilities regarding partner support.

#### **3.3 STUDY SITE**

The study was conducted at the three selected special schools of the Polokwane municipality in the Capricorn District of the Limpopo Province. The Capricorn District (CD) has five municipalities: Aganang, Blouberg, Lepelle-Nkumpi, Molemole and Polokwane. The study was conducted in the two municipalities of the Capricorn District, namely Polokwane municipality and Lepelle-Nkumpi municipality. Polokwane and Lepelle-Nkumpi municipality were chosen because they have the highest number of special schools and a lot of mothers with SID children as observed by the researcher at the specific hospital of the Capricorn District where the researcher was working.

Special school are schools that provide an education for children with a special education or disabilities. The selected special schools used in this study admit



mild, moderate and severe intellectual disability children and the conditions that the children are suffering from are Down syndrome, autism, severe intellectual disability, learning disability and others. The activities that are done at selected special school are vocational skills such as carpeting, art work, cooking, baking and flowers making.

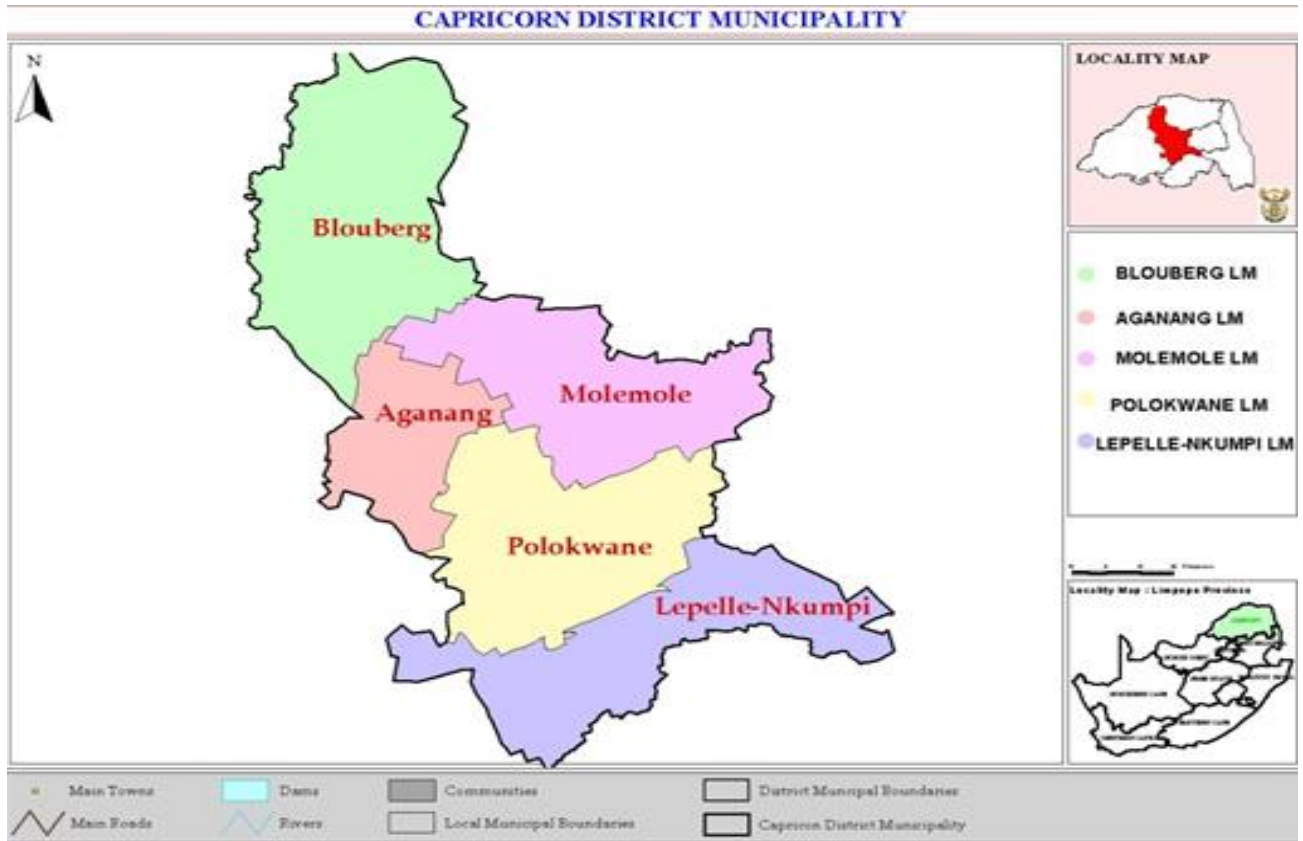
### ***Polokwane municipality***

The Polokwane Municipality (PM) is a local municipality located within the Capricorn District in the Limpopo Province of South Africa. It shares its name with the city of Polokwane (PLK) (formerly Pietersburg). Polokwane Municipality accounts for 3% of the total surface area of Limpopo, however, over 10% of the population of Limpopo resides within its boundaries. The municipality serves as the economic hub of Limpopo and has the highest population density in the Capricorn District. In terms of its physical composition is 23% urbanized and 71% rural. The municipality's largest sector of the community resides in rural tribal villages, followed by urban settlements. As of 2007, the Polokwane municipality was home to approximately 561,772 people. The black population in the city is approximately 94% of the municipal residents. The white population accounts for almost 5%, and the coloured and Indians are over 1% of municipal residents. Six of the eleven official SA languages can be heard in the streets, namely: Sepedi, Xitsonga, Tshivenda, IsiNdebele, English, and Afrikaans. The total number of special schools is five and the total number of special schools selected from Polokwane municipality in this study is two.

### ***Lepelle-Nkumpi municipality***

Lepelle-Nkumpi Municipality is one of the local municipalities within the Capricorn District Municipality in Limpopo Province. The municipality is located 55km south of the district municipality and Polokwane city. The municipality is rural with a population of 227 965 and covers 3,454.78km which is 20.4% of the district's total land area. The municipality is divided into 29 wards, four of them being a township called Lebowakgomo, one of the Capricorn District growth points. The total number of languages spoken in Lepelle-Nkumpi municipality is three northern Sotho, southern Ndebele, and Tsonga. The total number of special

schools is two and the total number of special schools selected in this study is one. Figure 3.1 below shows a map of Capricorn District Municipality.



**Figure 3.1 A map of Capricorn District municipalities**

### **3.4 RESEARCH DESIGN**

According to (Brink, et al., 2014), a research design is a set of logical steps taken by the researcher to answer the research question, form the blueprint for the study, and determine the method used by the researcher to obtain participants, collect data, analyse the data, and interpret the result. In this study, qualitative explorative and descriptive design was used.

#### **3.4.1 Explorative research design**

Explorative research design is when the researcher illuminates how a phenomenon is manifested and is especially useful in uncovering the full nature of a little-understood phenomenon (Hunter, Howes & Mccallum, 2018). Explorative design in this study was used to allow the researcher to explore the

experiences of mothers of children with severe intellectual disabilities regarding partners' support.

### **3.4.2 Descriptive research design**

A descriptive research design provides an accurate portrayal or account of the characteristic of a particular individual situation or group (Brink, et al, 2014). The descriptive research design in this study allowed mothers to describe their experiences regarding their partner support for their children with SID. Participants were allowed to describe their experiences based on the central and probing questions that were asked during data collection.

### **3.5 POPULATION**

According to Thacker (2020), a population is a complete set of people with specified characteristics. The study population consisted of all mothers of children with SID attending three special schools in Polokwane and Lepelle-Nkumpi municipality of the Capricorn District in Limpopo province for the academic year 2020. The accessible population is the portion of the target population that the researcher can access (Fetzer, 2020). The researcher used mothers of children with SID from three selected special schools of Polokwane and Lepelle-Nkumpi municipality of Capricorn District. The size of the population in this study was 2194 this is based on the total number of children in all the special schools.

### **3.6 SAMPLING**

Sampling is the selection of a subset of the population of interest in a research study (Turner, 2020). In this study non-probability, purposive sampling was used based on the researcher's judgment regarding participants that were knowledgeable of the phenomenal study (Turner, 2020). A non-probability purposive sampling technique was used to obtain participants in this study. A total number of twelve mothers of children with SID at three selected special schools were purposively selected. Table 3.1 below illustrates the characteristics of the participants.

**Table 3.1: Characteristics of the participants**

<b>Participant</b>	<b>Age</b>	<b>Marital status</b>	<b>Employment status</b>	<b>Both parents stay with the child on daily bases</b>	<b>Gender/ age of the child</b>	<b>Relationship with the child</b>	<b>Name of the school</b>
P1	51	Single	Unemployed	Yes	Female 08 years	Mother	Special school A
P2	38	Single	Unemployed	No	Male 13 years	Mother	Special school A
P3	37	Single	Unemployed	Yes	Male 09 years	Mother	Special school B
P4	62	Married	Unemployed	Yes	Female 11 years	Mother	Special school A
P5	33	Married	Employed	No	Male 08 years	Mother	Special school A
P6	39	Single	Unemployed	Yes	Male 14 years	Mother	Special school B
P7	40	Single	Employed	No	Male 18 years	Mother	Special school B
P8	44	Single	Unemployed	No	Male 13 years	Mother	Special school B
P9	32	Single	Unemployed	Yes	Male 07 years	Mother	Special school B
P10	27	Single	Unemployed	Yes	Female 08 years	Mother	Special school B
P11	63	Divorced	Pensioner	No	Male 18 years	Mother	Special school C
P12	46	Married	Employed	Yes	Female 09 years	Mother	Special school C

## **3.7 INCLUSION AND EXCLUSION CRITERIA**

### **3.7.1 Inclusion**

- Mothers of children with SID staying with partners daily were included in this study to get the daily experience of partner support.
- Mothers of SID children whose partners only come home / visit during the weekends or month end were also included in the study. The experiences of this particular group of mothers were crucial for examining the support that they received from their partners both at home and while they are away for work.

### **3.7.2 Exclusion**

- All mothers of children with SID staying with partners, those who were not available, or interested were excluded from the study as participation was voluntary.

## **3.8 DATA COLLECTION**

Data collection is defined as a precise, systematic gathering of information relevant to the research purpose and the specific objectives, questions, or hypothesis of the study (Burns & Grove, 2017). The purpose of data collection is to obtain information to keep on record, make decisions about an important issue, and pass information to others (Brink et al, 2014).

### **3.8.1 Recruitment of participants**

The researcher first contacted the principals of the three selected special schools and explained the study's outline contents. The email was sent to the principals following the phone conversation. Then the principals informed the parents that there is a researcher who wants to research partner support and requested the parents' permission to give their numbers to the researcher for the recruitment purposes.

After the mothers permitted the principals to give their numbers to the researcher, then the principals permitted the researcher to collect data and provided the contact list of the mothers of SID children so that the researcher could contact them and inform them about the study.

Recruitment of the participants was done telephonically because it was during the Covid 19 lockdown and the special schools were not allowing visitors. The researcher contacted the mothers one by one after the permission was granted by the principals, the researcher explained the outline contents of the study to the mothers and those who agreed, the date, time and place were set for the interview.

### **3.8.2 Data collection instrument**

Dejonckheere and Vaughn (2019) defined a semi-structured interview as a data collection method that involves asking participants open-ended questions and following them up with probe questions to further explore their responses and the topic of interest. The researcher used a semi-structured interview in this study because it has open-ended questions that allow the researcher and the participants to discuss the topic in more detail. Semi-structured interviews give the researcher rich, detailed data due to their open-ended nature and flexibility to ask probing questions. According to Dejonckheere and Vaughn (2019), one-on-one interviews using semi-structured interviews encourage participants to give a full picture of their situations and to respond to the probing questions.

According to Beck & Polit (2014), the interview guide is described as logically sequenced, self-prepared questions to be covered with each participant during the interview process. The interview guide consisted of one central question, the central question that was asked: “kindly describe your experiences regarding the support that you receive from your partner when caring for your severe intellectual disabled child” and five probing questions were asked to all participants.

### **3.8.3 Data collection process**

During data collection, the researcher followed COVID-19 regulations by requesting the mothers to arrange the room to be interviewed in a way that was compliant with COVID-19 regulations. The researcher put on a face mask sanitised his hands and maintained a social distance of 1.5 meters during the interview to comply with the COVID-19 regulations. The research also ensured that the mother’s hands were sanitised with hand sanitizer, the sanitizer was put in place in the room prepared by the mothers. The researcher provided the

mothers with disposable face masks before the start of the interview. The research monitored the mother's body temperature using a digital infrared thermometer before the interview.

The researcher conducted all the interviews. During the interviews, the researcher was with the participants only in the room to maintain privacy and allow the participants to be comfortable and express themselves. After obtaining permission, the interviews were voice recorded using a digital voice recorder. Data collection was done using Sepedi (appendix: B) and English (appendix: A) interview guides, as the participants spoke and understood those languages. The central question was: "kindly describe your experiences regarding the support you receive from your partner when caring for your child with severe intellectual disabled".

Field note was written to capture the participants' nonverbal communication such as mannerisms. Field notes refer to a written account of what the researcher sees and observes during interviewing participants (de Vos, Strydom, Fouche & Delport, 2011). Field notes were analysed with verbatim transcriptions to develop themes and sub-themes during data analysis. A total of twelve interviews were conducted. There was no prior determination of the sample size. Interviews were conducted until the point of data saturation was reached, where no new information emerged which was obtained after conducting the ninth interview. Ten, eleven and twelve interviews were conducted to confirm the saturation.

#### **3.8.4 Pilot study**

A pilot study is a small, scaled study conducted prior to the main study on a limited number of participants from a population at hand. The purpose of a pilot study is to investigate the feasibility of the proposed study and to detect possible flaws in the methodology of the proposed study (Creswell, 2013). A pilot study was done on three participants who meet the inclusion criterion, but those participants were not to form part of the sample. Data collected during the pilot were not included in the main study.

In this study, a pilot study was conducted at special school D, where three mothers of children with SID were interviewed using a structured one-on-one interview with an interview guide to test the feasibility of the interview guide. This

was necessary to determine whether the participants understood the interview guide's content and allowed the researcher to refine and improve the interview guide and the interview skills. Mothers used in the pilot study were not included in the main study to avoid bias as the mothers were already knowing the questions to be asked. The result of the pilot study indicated the need for the researcher to avoid asking leading questions, as well as the need for more probing questions to understand and obtain more information on the experiences of mothers of children with a severe intellectual disability regarding partner support. The researcher rephrased one of the probing questions.

### **3.9 DATA ANALYSIS**

Babbie (2013) defined qualitative data analysis as examining social research data without converting them to a numerical format to discover underlying meaning. Data analysis starts with a transcription of raw data generated from interviews. In this study, individual verbatim responses were transcribed from tape recording and those done in Sepedi were translated to English.

Transcription allowed the researcher to be acquainted with data and have a transcription that included non-verbal communication and gestures. The researcher reviewed all transcribed data to familiarize himself with data in preparation for the analyses. Analyses were based on Creswell (2014:186) method of data analyses as described in 8 steps in the protocol as follows:

**Step 1:** Each data set was translated, transcribed and consolidated into one document. This included the data from observations and field notes. At this stage, the researcher familiarized herself with the data, going through the audio-recorded data, pausing and rewinding the play of the recorded data to capture all the data into transcription. The researcher repeatedly played the recorded data to check the accuracy of her transcription, which created an opportunity to internalize data generated during the interviews.

**Step 2:** The researcher picked and acquainted herself with one data transcript. As data were being read repeatedly, the researcher wrote down a list of some ideas discovered through the data, also relating the phenomena in columns together while she was going through the data and relating the phenomena in



columns. She also related the phenomena in columns with supporting statements. These ideas were meaning given to the data at hand.

**Step 3:** The researcher then repeated the process in Step 2 with all individual data documents, still generating a list of topics or sentences that came to mind and described the experiences.

**Step 4:** The listed topics were then compared with data. These topics were then abbreviated for coding. Finally, the researcher revisited the data and wrote the codes next to the relevant topics in the margin.

**Step 5:** Topics that have a similar meaning were grouped. These gave birth to categories. Then, all statements that addressed each category were put together. Finally, further data reduction was made by grouping categories related to one another.

**Step 6:** The researcher, together with the supervisor reached a final decision on the abbreviation for each category, called themes.

**Step 7:** All data material that belongs to each category was put in one place, and the researcher conducted a preliminary analysis.

**Step 8:** Recoding was done, with meanings of the findings interpreted. Narrative passages were written to describe the findings of the study. However, lessons learned would guide the interpretation, and the results were compared with literature, ending with recommendations for future research studies

The themes and subthemes were submitted to the co-coder to review and confirm the themes and sub-themes. The co-coder used the Creswell method of data analysis. Consensus meetings were held between the researcher and the co-coder to finalise the themes and subthemes.

Co-coding process systematically transforms qualitative data into meaningful outcomes that present the data and answer the research questions (Adu, 2021). Elliot (2018) defined the co-coding process as analysing qualitative text data by taking them apart to see what they yield before putting the data back together meaningfully.

Saldana (2013) described co-coding processes as having two cycles, first cycle of co-coding processes can range in magnitude from a single word to a full paragraph to an entire page of text to a stream of moving images. In the second cycle of co-coding processes, the portions coded can be the exact same units, long passages of text, analytic memos about the data and even a reconfiguration of the codes themselves developed.

The role of co coder in qualitative research as described by Adu (2013) is to:

- Extracting relevant information from the data
- Labelling the extracts and developing codes
- Generating themes from the codes
- Addressing the research questions with the themes

### **3.10 MEASURES TO ENSURE TRUSTWORTHINESS**

Trustworthiness in this study was ensured by using four criteria of trustworthiness, which were credibility, dependability, confirmability, and transferability (Brink et al, 2014).

#### **3.10.1 Credibility**

Credibility refers to confidence in the truth and interpretation of data (Beck & Polit, 2014). In this study, credibility was ensured by the use of prolonged engagement and triangulation. Korstjens and Moser (2018) define prolonged engagement as when the researcher invests sufficient time to become familiar with the setting and context to test for misinformation, build trust and get to know the data so that he can get rich data. The researcher had a prolonged engagement with the participants in the field where each interview lasted 30-45 minutes per participant. Triangulation is when the researcher asks a different question, seeks different sources, and uses different methods. This study ensured triangulation by using different data sources including field notes and interviews with the tape recorder. Houser (2015) defines field notes as the researcher's observation of the participants' environment and body language, as well as any other information that may enrich the data. Field notes were written to capture non-verbal communication such as actions and signs displayed by the participants. Field notes were analysed with verbatim to develop themes and sub-themes.

### **3.10.2 Dependability**

Dependability refers to the provision of evidence such that if it were to repeat with the same or similar participants in the same or similar context its findings will be similar, the term thus refers to the stability of data over time (de Vos, Strydom, Fouche & Delport, 2011). Babbie and Mouton (2011) described dependability as to whether the study findings would be similar if it were to be repeated with the same or similar subjects, or if it was replicated in the same context. In this study, dependability was ensured by giving a detailed description of the research methodology that was used in the study, so that if there were a need to replicate the study with the same participants in the same context, another researcher would obtain the same result.

### **3.10.3 Conformability**

According to Polit and Beck (2012), conformability refers to findings that reflect the implementation of credibility, auditability, and fittingness. The extent to which the finding was based on the study's participants and settings instead of the researcher's biases. All research tools, including audiotaped records and field notes, were submitted to the supervisor and independent coder for analysis and co-coding. Thereafter the researcher, supervisor and independent coder had a meeting to compare and discuss the themes and sub-themes identified by both, where they were differences, the raw data was revisited, and a consensus was reached. Confirmability in this study was ensured by playing back the tape-recorded interviews with participants to check if what they had said is what they meant.

### **3.10.4 Transferability**

Transferability refers to applying the findings in other contexts or to other participants (Brink et al, 2014). The extent to which the findings can be transferred or applied in different settings. This study ensured transferability by using purposive sampling where participants were selected due to their knowledge. This meant that the study could be transferred to other participants that were different from the one the researcher selected and observed if the findings could be the same.

### **3.11 BIAS**

Bias is any influence that produces an error or distortion in the results of the study, which can affect the quality of evidence research, bias can occur in any step of the research process (de Vos, Strydom, Fouche & Delpont, 2011). In this study bias was avoided by selecting the simple population using the purposive sampling technique which allows the researcher to carefully select the sample based on the element that was related and was able to answer the research question and provide relevant information (de Vos, Strydom, Fouche & Delpont, 2011). Bracketing is putting aside what is known about the study topic to allow the data to convey undistorted information (Brink et al, 2014). Bracketing was ensured by writing down all the pre-conceived ideas before beginning the interview to avoid bias. Interviews were conducted as if nothing was known about the study. Bias was avoided by interviewing the participants using Sepedi and English as those languages were spoken and understood by the participants.

### **3.12 ETHICAL CONSIDERATIONS**

Ethics are standards or patterns of behaviour that direct moral choices about conduct and relations with others (Cooper & Schindler, 2011). In this study, the researcher adhered to the following ethical standard.

#### **3.12.1 Ethical clearance**

The researcher first obtained ethical clearance to conduct a study from the Turfloop Research Ethics Committee (TREC) (see appendix: G) with an ethical clearance certificate number of TREC/52/2021: PG.

#### **3.12.2 Permission to conduct the study**

Permission to access the special schools was obtained from the Department of Education in Limpopo province (see appendix: E). Permission was also granted by the principals of the three selected special schools (see appendix: G, H and I).

#### **3.12.3 Informed consent**

Informed consent comprises of three elements, information, voluntariness, and comprehension (Mary & Holmes, 2012). Sepedi and English informed consent form (see appendix: B and appendix: A) was obtained from each participant with an explanation of the study's topic, objectives and aim. Sepedi and English

written informed consent form were used as participants in the three selected special schools spoke and understood Sepedi and English. Participants were informed that participation was voluntary.

#### **3.12.4 Principle of confidentiality**

According to Burns and Groove (2011), confidentiality is a researcher's safe management of the research information data shared by the participant to ensure that it is kept private from others. In this study, confidentiality was ensured by assuring participants that data collected from them was not divulged to an unauthorised person or any other person not directly involved in the research without their permission and the researcher published the results with their identity protected by using numbers and alphabets in state of their names. Confidentiality in this study was ensured by keeping all the collected data in a secure place only assessable to the researcher, supervisor, and the independent coder.

#### **3.12.5 Principle of privacy**

Privacy is the freedom an individual has to determine the time, extent, and general circumstances under which private information will be shared with or withheld from others (Fouka & Mantzorou, 2011). In this study, participants' privacy was ensured by interviewing them in their homes where they felt free to respond.

#### **3.12.6 Principle of anonymity**

Participants' data should never be associated immediately and obviously with a name or any other identity (Moule & Goodman, 2014). In this study, anonymity was ensured by protecting the identity of the participants and participants' specific responses and information was not linked in any way with the participants. The researcher used numbers and an alphabet to hide the participant's identity.

#### **3.12.7 Principle of respect for a person**

People have the right to self-determination and treatment as autonomous agents. Thus, they can participate or not participate in the research study (LoBiando & Haber, 2010). In this study respect for a person was ensured by not forcing the

participants to participate in the study, this was achieved by telling the participants that participation was voluntary.

### **3.12.8 Principle of justice**

The principle of justice implies that all individuals and groups within the study are equal, and no group or individual will be privileged or disadvantaged because of their social position (Coughian, Cronin & Ryan, 2013). In this study principle of justice was ensured by not abusing the participants or exploiting the grounds of sex, race, religion, age, and class. Participants' rights were not violated, and they were all treated with dignity and fairness (Moule & Goodman, 2014).

### **3.12.9 Principle of non-maleficence**

Non-maleficence refers to a study that does not inflict any harm to participants (Flick, 2014). In research discomfort and harm can be physical, emotional, social, and economic (Groove, 2015). The study was conducted in a manner that allowed the researcher to avoid physical and psychological harm to the participants. This was achieved by carefully structuring the interview guide and monitoring the participants during the interview.

The study was conducted in a manner that allows the researcher to avoid physical or psychological harm to the participants, this was achieved by carefully structuring the questions and monitoring the participants for any signs of emotional distress which could be crying out louder. If emotional distress was observed the researcher stopped the interview for 15-20 minutes comforted the participant and assess the situation. If the participant recovered the researcher continue with the interview if not the researcher refers the participant to a public psychologist.

### **3.13 CONCLUSION**

This chapter described and discussed the research methodology, approach, study site and the design used in the study: population, sampling, and sample size: inclusion and exclusion criteria, data collection method, data analysis, and measures to ensure trustworthiness that include credibility, transferability, dependability, and conformability. Bias and ethical considerations include aspects such as ethical clearance, permission to conduct the study, informed consent, the principle of confidentiality, the principle of privacy, the principle of

anonymity, the principle of respect for a person, the principle of justice and the principle of non-maleficence. The next chapter will discuss the presentation of the findings of the study.

## **CHAPTER 4**

### **RESULTS AND DISCUSSION OF FINDINGS**

#### **4.1 INTRODUCTION**

This chapter presents the results of the data collected from the mothers of children with SID at the three selected special schools of Polokwane and Lepelle-Nkumpi municipality of the Capricorn District Limpopo Province. The characteristics of the participants were shown in Table 3.1. Tesch's inductive and descriptive coding technique was adopted for data analysis as suggested by Creswell (2014). Themes and sub-themes emerged during data analysis. The results are discussed based on the experiences of mothers of children with SID regarding partner support. A total number of twelve mothers of children with SID were interviewed until data saturation was reached.

#### **4.2 THEMES AND SUB-THEMES**

The theme is an umbrella constructed relevant to the research questions, which can be seen on some level of patterned responses (Flick, 2014). A sub-theme is a specific theme within a large theme (Flick, 2014). Seven themes and twenty-six sub-themes emerged during data analysis, as shown in Table 4.1



**Table 4.1: Themes and sub-themes**

<b>THEMES</b>	<b>SUB-THEMES</b>
1. Mothers' perceptions of the child's (dis)abilities	1.1 Physical and mental (dis)abilities
2. Mothers' initial experiences of having a child with a severe intellectual disability	2.1 Emotional experiences 2.2 Challenges to accepting the reality 2.3 Coping through acceptance
3. Mothers' experiences of partners' support with a child with a severe intellectual disability	3.1 Acceptance of the child 3.2 Involvement and interest in the child 3.3 Caring about and loving the child 3.4 Positive relationship with the child 3.5 Emotional support through encouragement 3.6 Instrumental support through sharing supervision and caring role 3.7 Informational support 3.8 Financial support
4. Mothers' challenging experiences of partners' support with a child with a severe intellectual disability	4.1 Partners' challenges to accept the child 4.2 Partners' lack of emotional support (uninvolved and distant) 4.3 Partners' lack of instrumental support 4.4 Parenting challenges 4.5 Marital relationship challenges 4.6 Financial challenges
5. Mothers' experiences of caregiver burden related to partners' support	5.1 Instrumental burden 5.2 Financial burden
6. Mothers' experiences of coping with caregiver burden related to partner support	6.1 Internal coping (acceptance and spiritual coping) 6.2 Informational support 6.3 External social support 6.4 External financial support
7. Mothers' recommendations for partners' support with a child with a severe intellectual disability	7.1 Recommendations for informational support 7.2 Recommendations for coping strategies

## 4.3 PRESENTATION OF THE FINDINGS

### 4.3.1 THEME 1: MOTHERS' PERCEPTIONS OF THE CHILD'S DISABILITIES

Mothers in this study are having the ability to notice and understand their children's disabilities that are not obvious to other people. Mothers' perceptions of the child's disabilities have one sub-theme namely, physical, and mental disabilities.

#### 4.3.1.1 Sub-them 1.1: Physical and mental disabilities

The mothers of children with SID shared their experiences regarding the different symptoms and behaviours presented by their children. The mothers described how they understand their children's conditions. The findings indicates that mothers had different understanding on their children's conditions. Some mothers thinks that their children are slow learners based on the pattern of behaviour of their children as evidence by *P2: I don't know the condition my child is suffering from what I know is that my child is a slow learner. If you send him to bring you something he just comes with the wrong thing the one you didn't send him for and he does not understand well he forgets some concepts easy. At the hospital, they didn't tell me what condition my child is suffering from, and he is able to walk and talk.*

*P6: Aaaa my child is just a slow learner he has difficulties with understanding that he is unable to write and has poor concentration that is what I know about him. Again, his mind is like the mind of a 2 to a 3-year child his mind is not corresponding to his age*

A mother of a 08 year old severe intellectual disabled child was not able to identify the child disabilities and was assisted by the teachers at the school the child was attending: *P10: Teachers did explain to me when she was at preschool, teachers saw the child that is a slow learner as compared to her age group her developmental milestone was delayed not matching her age. Teachers told me to take the child to the clinic then I took my child to the clinic.*

Some mothers were able to identify their children's disabilities at early stages and were able to sake assistance. These mothers were informed of the specific diagnosis of their children as evidenced by:

*P3: At the hospital, they told me that my child is suffering from severe intellectual disability, in short, my child cannot do all the activities without help he cannot bath himself, he cannot feed himself and he is not toilet trained*

*P4: My child is suffering from Down syndrome, my child is able to walk but to talk she is trying, able to call his brothers and sisters names.*

*P5: He is suffering from autism, at first, we didn't know that the child is having this condition we knew it at a later stage by our observation seeing that the child is having delayed milestones as compared to his age group. He develops later as compared to his age group*

*P7: My child is having mental retardation, as far as I know, mental retardation is a condition whereby a person has...what can I say mentally disabled. Three months then he was diagnosed with meningitis, and he was admitted to the hospital. He stayed in the hospital for almost three months he was on a ventilator when they tried to remove him from the ventilator he was not coping well. He had continuous convulsion then was given treatment then we were discharged. Then when he grows up, I realised that he had delayed milestones when he was supposed to sit, walk, and talk he didn't.*

*P8: My child is suffering from speech and hearing he is not able to speak well*

*P9: The doctors told us that our child is having mental disability he cannot be the same as other children he will be unable to do some of the basic things like bathing himself, writing and talking well as compared to normal children*

*P10: Nurses at the clinic told me that my child is having a disability and they told me that my child is having delayed milestones when she was expected to walk, she didn't, and even now she is not yet toilet trained. They told me that my child is a slow learner, and they are right because she is a slow learner, she takes time to understand things, but my child is able to talk*

*P11: my child is suffering from Down syndrome, and they told me that his hand coordinates his mind is slower than his age*

A 46 year old mother of a 09 year old severe intellectual disabled child expressed that she discovered the diagnosed of her child by reading the psychologist report

*P12: I just see on the psychologist report saying my child is having a severe intellectual disability, but I didn't get an explanation of what severe intellectual disability means. They said she is a slow learner, and she has difficulties in understanding things well, is what they told me, but I observed it by myself.*

#### **4.3.2 THEME 2: MOTHER'S INITIAL EXPERIENCES OF HAVING A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

The findings of the study indicate that it was very difficult for partners to accept the child's disability at first as some of the partners were very emotional and felt pain and some were scared and lost hope in each other. A mother's initial experiences of having a child with a severe intellectual disability have three sub-themes namely: Emotional experiences, challenges to accepting reality and coping through acceptance.

##### **4.3.2.1 Sub-theme 2.1: Emotional experiences**

Emotional experiences are the result of what impacts the person and how those situations are comprehended and signified by the person (Horta, 2014). The findings of the study indicate that partners were very emotional to give birth to a child with a severe intellectual disability, as they further stated that every parent when pregnant wishes to give birth to normal child. Most partners expressed their emotions by crying, some were sad and some lost hope to the child and their mothers.

It is evident from the following quotations:

*P1: we became very emotional sad, cried, and felt pain like her parents, and you know that no parents wish to have that kind of child.*

*P3: truly speaking sir the news made me very emotional I cried because every parent when she is pregnant wishes to deliver and have a normal child. It was worse when told that the child will not be able to do things on his own, for example, basic things like feeding himself, bathing and even talking and writing that one made me emotional, and I felt sad.*

*P8: we were scared that our child will be mute forever because when he was young, he didn't speak when he needs something he was just pointing it without speaking now he is able to talk. First time I was just scared.*

*P9: I and my partner felt pain, we cried, and we were very emotional we asked ourselves what we did wrong in this world to end up having a disabled child. Again my partner was emotional and feeling pain because during pregnancy he was there for me supporting me and was very happy saying we going to have a child. After the birth of the child when they told us that the child is disabled, he was very emotional, sad, and lost hope in us.*

#### **4.3.2.2 Sub-theme 2.2: Challenges to accepting the reality**

The findings of the study revealed that mothers of children with severe intellectual disabilities didn't accept the situation they were faced with by not accepting their children's condition. Most mothers didn't accept their children's disabilities when told for the first time as they were not expecting to deliver children with SID as evidence by: *P4: When they told me for the first time I didn't understand and I didn't accept but as time goes, because I stayed 2 months at the hospital then they keep on explaining to me the condition of the child and giving me health education about the child's condition then I ended up accepting my child's condition*

*P6: Yoo, at first, I didn't accept my child's condition and the preschool he attended called me and told me I didn't accept, and I refused.*

*P7: Yoo I was so emotionally disturbed I cried I couldn't accept it, was unacceptable I felt like God is pushing me, I didn't expect to have a child like him you know it was very painful for me I couldn't accept at first but when time goes, I realized this is the life I start to accept.*

A 39 year old mother of a 14 year old severe intellectual disabled child was referred to the social workers and to the hospital by the school teachers but she refused to go due to denial. As evidence by: *"at preschool, they arranged social worker to talk to me about the child, but I still didn't accept, and I even chased the social worker away. I was not accepting what they were telling me about my child I told myself that at preschool teachers there they hate my child. Then at the age of 7 to 8 years, I started to see that the social worker and preschool*

*teachers were right about the condition but still, I didn't accept then they gave me a referral letter to take the child to the hospital I again told myself that these people are fighting me. When I compare my child to his age group, my child was slow and then I realised that my child is having a problem then is where I accepted but my child never got sick you see" P6*

A 27 year old mother of a 08 year old severe intellectual disabled child was told by the school teachers that the child is having SID, she denied by saying the teachers they don't like her child or they are fighting them and their child. P10: *truly speaking that was a difficulty, at first, I was in denial not accepting what preschool teachers told me about my child, that my child is having some disability I thought they don't like my child, or they are not good teachers they are unable to teach my child. Then I was thinking of taking my child to town school maybe the town teachers there will have an interest in my child and be able to teach my child unfortunately, I didn't have money to take my child to town schools.*

A 38 year's old unemployed mother of a 13 year old severe intellectual disabled child expressed that she sometimes ask herself why is the other child normal and the other one intellectually disabled: *"I just feel pains and sometimes have difficulties in understanding why my 7 years old child is normal and his brother is disabled that's the difficulties I sometimes do have" P2.*

#### **4.3.2.2 Sub-theme 2.3: Coping through acceptance**

Other mothers described that it was easy for them and their partners to accept the condition of their children because they were alerted by the delayed milestones and others had a history of the intellectual disability in their families. Partners supported each other in the process of accepting their children with SID and their relationships didn't change due to the conditions of their children. As evidence by: *"when they diagnosed him, we just accepted that we are having this different child from others, and we told ourselves that this is what God gave us. It didn't come as a shock to us because we saw that our child has delayed milestones before diagnoses and after diagnoses, we just accepted. The treatment was the same as I already told you we accepted our child 's condition and tried to find a way of raising a different child nothing changed" P5*

*P12: this child I was given when she was 3 months, and she was a very sick baby then I took her to the hospital I found out that she is HIV and a slow learner there. Myself I noticed her disability before the preschool teacher noticed her because I saw her while playing with other children that mine is disabled. Because I didn't have full knowledge about their mental condition at school, they called me and told me that my child has a disability, but I told them to understand her and tolerate her until she did grade R and they condoned her up to grade 2 until at school were enough about her, they started to beat her when failing to write. I took her to a psychologist who confirmed the disability, and we didn't have a problem with her disability because in our family we do have a child similar to mind my little sister's child born in 1995 has that disability and attended special school so it was not a shock because we do have that child in my family*

A 62 year old mother of 11 years old child with intellectual disability described how her partner reacted after disclosing to him the condition of their child. She expressed that she and her partner accepted their child with SID as a gift from God, as evidenced by: *P4: I called him while I was at the hospital and explained to him the condition of the child and I told him that is why I am still at the hospital, and I cannot come home. When he come to the hospital to see the child, I didn't see him having a problem with the child he accepted what God gave us. I didn't see any changes in our relationship we continued with life the way we used to. We both accepted the child.*

*P1: But because we gave birth to her, and she is here with us we have to accept her the way she is.*

#### **4.3.3 THEME 3: MOTHERS' EXPERIENCES OF PARTNERS' SUPPORT WITH A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

The study's findings indicated that some mothers of children with SID had support from their partners. This was supported by the eight categories that emerged from the finding of the study. The eight categories are acceptance of the child, involvement and interest in the child, caring about and loving the child, positive relationship with the child, emotional support through encouragement,

instrumental support through sharing supervision and caring role, informational support, and financial support.

#### **4.3.3.1 Sub-theme 3.1: Acceptance of the child**

The study's findings showed that some partners accepted their children with SID the way they are and were proud of them, as they didn't hide their children at home but were able to walk around with them. Some partners the way they accepted their children with SID they were able to take long drive with their children and walk with them to the shops.

It is evident from the following quotation:

*P1: My partner is proud of her, and he is able to walk around with her.*

*P2: My partner is proud of my child; he is able to walk around with him together with his younger brother.*

*P4: My partner is proud of my child because he is able to go to the shops with him and all in all he is not having problems with the child.*

*P5: My partner is proud of our child he sometimes took him to parks and takes a long drive with him as my child likes the car too much and again drives him to town involving him in the same activities.*

#### **4.3.3.2 Sub-theme 3.2: Involvement and interest in the child**

The findings of the study indicated that some partners were involved and participating in the care of their children with SID, as they were showing interest in knowing the progress of their children's conditions by asking their mothers the hospital feedback if they didn't go with them. Some partners were able to assist their children with SID with their school work by asking them what they did at school.

It is evident from the following quotation

*P1: My partner is asking for hospital feedback and then I do give him the feedback. My partner is a caring person and is our norm at our house to update each other about the child even when I go to the hospital for her appointments a do report to him.*



*P2: My partner is asking for hospital feedback if he didn't manage to go with us, then I tell him everything that happened at the hospital.*

*P4: My partner did ask for feedback then I start giving him the feedback from the hospital for example the current condition of the child whether she is improving or not and the next appointments dates*

*P5: My partner is involved, and he is a partner who is involved you see, most of the time I was going to the hospital alone, but I was informing him because he was working in another province far from us, but I was updating him with everything they did and said about the child.*

*P6: When my child is back from school, he will ask him how he spent his day, what did they do at school and even ask him to show him what they did. He is asking for everything and he sometimes takes the child by himself to the hospital telling me I don't present the child's condition well at the hospital. You know us, as a woman, some of the problems we hide, and he blames me for that.*

#### **4.3.3.3 Sub-theme 3.3: Caring about and loving the child**

The findings of the study indicated that partners of children with SID are taking care of the children and showing love to the children. Some partners could remember their children's important days like birthday days and on those days, some buy cakes and presents for them and celebrate with them while others throw parties and take them out to celebrate with them and their friends.

It is evident from the following quotation:

*P2: My partner is able to remember the child's birthday and he buys a cake for him then we celebrate together. Sometimes we just buy a cake for him at any time. If we didn't have money for his birthday, we buy the cake when we have money and celebrate after.*

*P4: We do buy Christmas clothes for her using her grant money we even do her hairstyles*

*P5: My partner doesn't forget our child's birthday the first thing he does on his birthday is he buys cake for him and due to his condition, he cannot do many activities. My child doesn't like noise so on his birthday we don't invite people we*

*just celebrate as a family and buy him his favourite gifts. We buy Christmas clothes for him sir*

*P8: Yooo my partner is buying a cake for him doing braai for him and inviting his friends*

*P12 My partner remembers our child's birthday and we do celebrate birthdays, last week was my child's birthday my partner throws her a big party and sometimes during her birthday he took her out with her friend to celebrate her birthday*

Some partners were able to look after their children with SID when their mothers were busy with house hold duties and some children were more used to play with their fathers than their mothers. As evidenced by: *"The child also loves his father more than me because she is always with him playing with him as you know us, women, we always busy with household work I spend little time with her than his father"* P1

#### **4.3.3.4 Sub-theme 3.4: Positive relationship with the child**

The findings of the study showed that partners have a positive relationship with their children with SID as they show them love, support, and encouragement by assisting them with basic needs.

It is evident from the following quotation:

*P1: I don't experience any problem with my partner, we don't fight we give our child love so that she can grow up knowing that we love her that's all-other things I will be laying my partner is sweet doesn't have any problem*

*P4: my experience regarding the support that I get from my partner is that: my partner is not a short temper to my child he understands the child very well. my child uses sign language to talk to my partner and he is understanding the language he even understands what the child is saying or needs for example when she needs food, she will point to the kitchen then my partner knows that she needs food and make food for her. Anything she needs just point it and his father does it for her without any problem.*

*P12: My partner is supportive; he is able to play with the child and when we watch TV she is always sitting with my partner or next to him and he accepted the child's condition.*

A 39 year old unemployed mother expressed how the partner is loving and supporting their 14 year old child with SID such as teaching him how to write and bath. As evidenced by: *“Look my child was staying with his grandmother but since he started staying with us, he is now able to understand and do some things because my partner is teaching him how to do things like writing. My partner was interacting with the child very well like the way he interacted with me there were no changes and the support that I got from him as I already told you he teaches our child many things that even I cannot teach him. He was unable to bathe himself then my partner taught him how to bathe himself, he was taking his time, taking him to the bathroom and showing him the whole process of bathing. My child is unable to write my partner will sit with him on a table and teach him to hold a pencil and even to write” P6*

#### **4.3.3.5 Sub-theme 3.5: Emotional support through encouragement**

The findings of the study indicated that mothers of children with SID are receiving emotional support from their partners, they give them support, confidence and hope regarding their children by saying to them these problems of disability affect many families not them only. Most partners of children with SID they were always there for their mothers of their children with SID emotionally by always supporting them and encouraging them to be strong for having children with SID and not to be short tempered on their children.

It is evident from the following quotation:

A 51 year old mother of a 08 year old girl with severe intellectual disability described the emotional support that she receives from her partner: *“The support that I get from my partner is emotional support, my partner supports me emotionally by saying to me that this problem is everywhere and, in every family, you're not the first person to have a child with severe intellectual disability. Again, he told me that even though I was not expecting to have this kind of child, but he*

*encourages me to accept the child. My partner is very supportive he does not want to see me being emotional, sad or blaming myself to have a disabled child".*  
*P5: Sometimes I become emotional about this child, and it became difficult hard for me to take care of this child then my partner is there for me to comfort me and support me emotionally*

*P6: My partner is that person who always supports me and gives me courage, telling me not to be short temper towards the child and he just supported me and said to me that you woman this kind of situation you always not accepting it plus as for firstborn, you know as a woman we want to enjoy first born you know otherwise, he is supporting me*

#### **4.3.3.6 Sub-theme 3.6: Instrumental support through sharing supervision and caring role**

The findings of the study indicate that mothers of children with SID receive instrumental support from their partners as their partners are giving them support by looking after their children when they are not home and accompanying them to the hospital for their children's hospital visits.

The following quotations evident the sharing of the supervision and caring role by mothers and their partners:

*P1: Other support my partner looks after my child when I am not home and he is going with us for the child's hospital appointments but not every appointment, because some of the appointment's clashes with his piece's jobs. Truly speaking if he is available, he goes with us. When I have societies to attend and when I do house duties my partner took over and looks after her.*

*P2: My partner always accompanied my child to the bus stop everyday morning when going to school and when I am not around, he is washing his clothes. My partner is going with us to the hospital for the child's appointment and sometimes he goes there alone with the child, my partner is a good person*

*P4: My partner is supportive in the care of my child he is able to look after her when I am not around. When I am not home my partner will wait for the child's transport to receive her then from there he will change her school uniform and do food for her to eat. He will stay with her until I come back.*

*P8: My partner is helping me with the care of the child and is taking much care of him more than other children we have*

*P12: My child is HIV positive taking treatment every month and my partner is accompanying us because our clinic is far and between mountains and every month, he does remind us of her clinic appointments. When we are not there, he takes the child to the clinic by himself*

A 39 year old mother of a 14 year old boy with SID indicated that because their child is in his puberty stage, his father is the one who is now assisting him with the personal hygiene. As evidenced by: *"Yaa at the age of 12 and 13 I was still bathing him, and it was difficult because he is a man if he was a woman it will be better, I had difficulties there. And my partner told me to stop at some point and he took over because a man needs to be shaved and it was too much for me"*  
P6.

#### **4.3.3.6 Sub-theme 3.7: Informational support**

The findings of the study indicated that mothers of children with SID are receiving informational support as their partners are searching for information about their children's condition and with little information, they find about the condition they share it with the mothers. It is evident from the following quotation

*P5: my partner is showing us support through his care for our child. He is searching about the child's condition as I do so that he can have full knowledge and understanding about our child's condition so that he can assist with the care of the child. My partner is supportive as I already told you that we are doing research about his condition because this condition is new to us. With the information from our search, we think we can come up with solutions on how we can take care of this child.*

*P12: My partner is giving me information concerning the child's condition if he hears something on the radio relating to the child's condition, he calls me and lets me know*

A mother of a 14 year old boy with SID expressed that she was getting the informal support from the family members as well. As evident by: *"my family and my partner advised me to follow my child's school 's order to take the child to the hospital for assessment as advised and look for special schools for him" P6*

#### **4.3.3.8 Sub-theme 3.8: Financial support (Positive feelings)**

The findings of the study show that mothers of children with SID are supported financially by their partners to provide for their children, this is supported by the partners giving them money to buy a school uniform and pay their child's school transport and school fees.

It is evident from the following quotation:

*P2: What I like about my partner is that when buying things like clothes he buys the same clothes for all of our children. Me and my partner I combine money and buy uniforms for our child. Sometimes my partner gets piece jobs he is a driver having public and sometimes is a painter with that piece job money we are able to buy uniforms for our child. All in all, we just assist each other with money at home, for example, today he went to his granny 's house to make a fence and coming back he will give me that money he is supporting us my partner*

*P6: My partner assists me by buying school uniforms for our child. I buy the uniform during the year when they gain weight then new uniform is needed his father buy and we buy Christmas clothes for him, and we start by layby and after 3 months we pay off the clothes. We do buy for all of our children*

*P8: My partner is supporting us financially he is giving me money to take our child to the hospital for check-ups and buy clothes for my child. My partner is paying for school transport for my child*

*P12: Before my child gets a grant, my partner was paying the school fee because by then I was not working. Sometimes he just came home with new clothes for her, he is supporting us truly speaking financially he is there for the child.*

#### **4.3.4 THEME 4: MOTHERS' CHALLENGING EXPERIENCES OF PARTNERS' SUPPORT WITH A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

The study's findings indicated that some mothers of children with SID received support from their partners while others mothers of children with SID had challenging experiences of receiving no support from their partners. This is supported by the study's findings as partners reject and don't accept their children. Six sub-themes emerged from theme four namely: Partners' challenges in accepting the child, Partners' lack of emotional support (uninvolved and distant), Partners' lack of instrumental support, parenting challenges, marital relationship challenges and financial challenges

##### **4.3.4.1 Sub-theme 4:1 Partners' challenges to accept the child**

Some partners and their family members of mothers of children with SID they rejected their children by saying in their families they don't give birth to children with SID that children were basted children. Some partners of mothers of children with SID were very shy to have children with SID as they were not able to walk with them in public and not able to take them to family gathering and to talk about them to people.

It is evident from the following quotation:

*P3: My partner is not proud of the child, and he cannot walk around with him, he is shy to talk about him to his friends because he fails to accept the child's condition.*

A 40 year old mother of an 18 year old child with SID described how her partner reacted after being told that the child is severely intellectual and physical disabled *"when the child grew, I called him and tell him that the child has physically disabled, he had right Hemi paralysis of the leg he is limping when walking the right arm is not working and he cannot even talk well. My partner told me that her sister told him that my child is not his because let me put it in Sepedi 'yena ga belege digole' (I don't give birth to disabled children) that is what my partner said to me, with those words he said to me the once I just told you we stopped communicating he never called and never ever wanted to see our child"* P7.

A 32 year old mother of a 07 years old boy with SID described how her partner reacted after the doctor disclosed the diagnosis of their child: *P9: After delivery, after the doctors told us that the child is disabled, he just pulled off stopped supporting us and I was left alone with the child he is not proud of him because he is not supporting us at home, and he is shy to have a disabled child he cannot even walk around with him cannot take him to our family gathering the child is always at home. Am I who takes him around during his hospital visit? I think for him to do what is doing maybe he didn't expect us to have a disabled child.*

A 27 year old mother of 08 year old girl with SID expressed that her partner was very supportive during pregnancy however the acceptance of the child with SID was a challenge: *"My partner was supporting me when I was pregnant but after finding out that our child is having some disability he changed and told me that in his family there is no one with a disability and that child is not his. Yes, he did support me when our child was still young but that changed when we realized that the child has some disability. First, my partner was in denial when they told us that our child is having a disability and my partner was very sad than me at first, he had denial and even started to reject the child. We were not happy in the house; his family came and told me that my child is not their son's child because in their family there is no disabled child ever this disability is new in their family. Meaning this child is a basted child and made her outside"* P10

*P11: Aaaa my partner likes shoulder he did not accept the child's condition.*

#### **4.3.4.2 Sub-theme 4.2: Partners' lack of emotional support (uninvolved and distant)**

The findings of the study showed that some partners of mothers of children with SID showed emotional support and others didn't showed any emotional support, this is supported by the findings of the study whereby the partner doesn't offer mothers reassurance, empathy, comfort, and acceptance of the children. Some partners of mothers of children with SID distanced themselves after knowing that their children are having SID, as some mothers called them to let them that they delivered children with SID, from there their partners stopped calling them and distanced themselves from them and their children.



It is evident from the following quotation:

*P3: After giving birth to this disabled child of ours my partner distanced himself from us, I don't know whether he was scared of the child or what. The support I got during pregnancy disappeared after giving birth to this disabled child. My partner as I already said distanced himself from us after the news with regard to this child so I cannot tell you how he felt when we first told him about the child's disability. I didn't understand his feelings serious. This child is my burden he doesn't ask anything from the hospital.*

*P7: My partner was never there for me he never supported me. He knew about the child's condition and when we were at the hospital, he used to call me, and we were talking about the child's condition but after there he never showed any kind of support. I did tell him that the child is in the hospital and admitted sick and has a disability a few months later he stopped calling, you know*

*P10: My partner when he saw that indeed our child is slow and has a disability, started to turn his back to us and he lost interest in knowing the condition of the child and never showed interest in the child. You see nurses at hospitals teach us how to take care of the child but my partner didn't want to learn anything about the child's condition.*

*P11: My partner was not spending quality time with us at home, he was avoiding us. He was leaving the house early in the morning and come back home later, we lacked his support at our home, and he is not supportive.*

#### **4.3.4.3 Sub-theme 4.3: partners 'lack of instrumental support**

The findings of the study indicated that mothers of children with SID lack instrumental support from their partners as some mothers went to seek medical assistance alone as their partners were not there to support them as they stepped back after the diagnosis of their children. Some partners of mothers of children with SID never supported their mothers of their children with SID, they never went with them to the hospital for their children as appointments.

It is evident from the following quotation:

*P3: My experience regarding the support that I get from my partner is that my partner is not supportive in the care of this child since they told us about the*

*condition of the child, he once runaway. I don't get full support from him truly speaking. As for my child's hospital visits, my partner is not going with us, I go alone with my child.*

*P7: I took the child to physiotherapy, speech therapy and occupational therapy but my partner has never been there for me. Yaa that is it I have never had support from him.*

*P9: My experience regarding the support I receive from my partner is that I don't receive any support from my partner. Hospital appointments and session with social worker and psychologist is my responsibility I go alone. Even in the house, I am still responsible for my child. My partner after knowing that the child is having a severe intellectual disability, left us.*

*P11: My partner was not going with us to the hospital for the child's hospital appointment, because after his operation they told me to bring the child for check-ups but I failed to take the child back for check-ups because I was depending on my partner because was the one who knows Pretoria and by then I didn't know how to drive but because he was not going with us not supporting me, I ended up not honouring his appointment.*

#### **4.3.4.4 Sub-theme 4.4: Parenting challenges**

The findings of the study indicate that partners of children with SID they were having disagreements on how to treat and raise their children with SID the findings of the study support this were by mothers don't want his partner to be hard on their child with SID. This causes a conflict to the parents as the two parents may differ on the actual methods to follow in parenting their children.

It is evident from the following quotation:

*P2: But the other thing I do not like about my partner is that he is hard on my disabled child, look I am having two boys the other one is 7 years, and he is normal, and my partner wants to treat them the same and I told him that it is not possible, but he forced to do that and I don't like it. My partner says my disabled child is a man and he want to teach him manhood things and sometimes he became hard on him if he can't do what he wants him to do.*

*P12: Me and my partner we didn't have problem at home we continued the same way as before, but I had problem with my partner because he called his family member and told them that our child is having mental disability and they must treat her different from other children. At first, I had problem thinking that he is exposing her but at the end I realised that he was helping her so that if in case we leave her with them they must know how to handle her.*

#### **4.3.4.5 Sub-theme 4.5: Marital relationship challenges**

The findings of the study reveal that partners' relationship changed after their partners know the condition of their children, this was supported by the findings of the study as the mothers stated that their relationship changed after the delivering of their children with SID as they were blamed for delivering children with SID. Partners of mothers of children with SID left their homes, some named their children as basted children and others filed divorce after birth of their children.

It is evident from the following quotation:

*P3: Eish things changed between me, and my partner and I think is because of this child as he blames me for delivering this child.*

*P9: The challenge we had is that we sometimes have arguments about the child, and he left us alone at home and the child's responsibility was left with me.*

*P10: The relationship is no longer going well due to this child. He is questioning why I am having to disabled child because in his family there is no one with a disability and he is saying that our child is not his but is a basted child. The relationship is bad is not the same as before, he is there in the house, but we are not good he doesn't look after our child.*

*P11: After the diagnosis of my child life was not good and my partner filed for a divorce.*

#### **4.3.4.6 Sub-theme 4.6: Financial challenges**

The findings of the study indicated that some partners of mothers of children with SID were unable to provide for their children with SID due to unemployment, this is supported by the findings of the study where mothers stated that their partners were giving them all kinds of support but financially, they were not supporting them due to unemployment. *P1: My partner is supporting me with everything but as I already told you that he is unemployed, and financially he does not support me. We just support our child with what we have*

*P4: The challenge that I experienced from my partner is that due to loss of his job when we need financial support from him sometimes, he fails to assist us, and I feel like I am asking too much from him knowing that he is jobless. He sometimes isolates himself and set alone kept quite when I look at him, I just think he is having stress because he is unable to take care of us and that issue stresses me too. Difficult times that I experienced is when my partner lost his job because my child grows up as a sick child and we had to take her to the clinic 3 times and the hospital 2 times for her sickness and check-ups. Financially we were not stable sometimes borrowing transport money from other people.*

A 63 years old divorcee, a mother of an 18 years old child with SID child expressed that she has financial challenges because she has a total of five children and she is the only one taking care of all these children as evidenced by: *“You know the difficulty is that she is not the only child you see she is number five of my children and I was the one who takes care of all of them even before divorcing my partner was not there for us. He was taking my bank card saying a man is the one who must take care of my bank card and he will take my money and spend it somewhere else then my child suffers then I removed her at school hostel due to money problem and become day scholar is what I suffered” P11*

#### **4.3.5 THEME 5: MOTHERS' EXPERIENCES OF CAREGIVER BURDEN RELATED TO PARTNERS' SUPPORT**

The findings of the study showed that mothers of children with SID have strains in the care of their SID children. This is supported by the two sub-themes that emerged namely: instrumental burden and financial burden.

#### 4.3.5.1 Sub-theme 5.1: instrumental burden

The findings of the study indicated that some mothers of children with SID were taking care of their children with SID by themselves and attended hospital appointments for their children with SID alone without their partners. As evident by:

*P4: My partner is not attending the hospital visits with me and our child, the hospital visit is me alone.*

*P7: As I already mentioned my partner has never attended any appointment with me, I was all by myself going to physiotherapy, and speech therapy I was going there by all myself he was never being there.*

A 32 year old mother of a 07 year old boy with SID described how the burden of caring affect her because of lack of sharing supervision and caring role with the partner “*my partner is not supportive because I have to hire someone to look after my child when I go to my piece job while he is home doing nothing*” 09.

A 37 year old mother of a 09 year old boy highlighted that it is difficult to attend social functions or going for shopping without the support from the partner. “*Eish difficulties came when I have to go shopping because this child needs total care for example feeding, nappy changing, dressing, and undressing him so is difficult to leave him with someone or even a neighbour because he needs total care. Sometimes as a woman, you need to go to women’s societies, funeral but with this child, you cannot go and attend such, which is a challenge for me*” P3.

Lack of instrumental support was also experienced by a mother who was pregnant with her second born as evident by: “*I had a difficult time taking care of my child last year, when I was pregnant with my second born, you know when you are pregnant some of the activities you cannot do them and even the energy drop. It was difficult for me to bathe my child and even to take her to the hospital for her appointment it was too much for me because my partner refused to go with me*” P10.

#### **4.3.5.2 Sub-theme 5.2: Financial burden (Negative feelings)**

The findings of the study indicated that some partners of mothers of children with SID, they don't support them financially, this is supported by mothers paying their children school transport, buying school uniform and hiring transport for hospital appointments without partner's financial assistance.

It is evident from the following quotation:

Mothers of children with ASD found to be the once supporting their children financially as evidenced by: *"Is me who buys school uniform my partner doesn't care and he doesn't even know that the child is wearing a uniform to school" P3. P7: I pay my child school fee by myself, and I even buy school uniform for my child*

*P9: I am using his grant money and sometimes my own money from my piece job to pay his transport because my partner is not supportive, he doesn't help with the transport money he doesn't care whether the child is going to school or not.*

*P10: I buy school uniform for my child because my partner told me that he cannot buy the school uniform for my child.*

#### **4.3.6 THEME 6: MOTHERS' EXPERIENCES OF COPING WITH CAREGIVER BURDEN RELATED TO PARTNER SUPPORT**

The study's findings showed that mothers of children with SID have overcome the strains in the care of their children with SID. This is supported by the four Sub-themes that emerged from the study namely: Internal coping (acceptance and spiritual coping), Informational support, External social support, and External financial support.

##### **4.3.6.1 Sub-theme 6.1: Internal coping (acceptance and spiritual coping)**

The findings of the study show that mothers of children with SID have managed to deal with their stressful situations regarding their children with SID. This is supported by the findings of the study as mothers accepted their child's condition through God (spiritually). Some mothers of children with SID believed in God and

their believes made them to accept their children's conditions and be able to care for them.

It is evident from the following quotation:

*P4: I don't have any questions brother; I just pray to God to just be with us so that our child's condition can improve and be the same as other children and be able to do things on her own*

*P11: I was scared when they told me at first but when they told me that after an operation, he will be fine then became fine and relaxed and I accepted the child's condition as a gift from God. My God give me strength if it was not God due to his strength, I think by now I would have a stroke but here I'm still strong and healthy taking care of my child.*

#### **4.3.6.2 Sub-theme 6.2: Informational support**

The findings of the study indicated that some mothers of children with SID received health education and information regarding the condition of their children with SID from health care workers and with that information, mothers accepted their children's condition. Some health care workers social workers, psychologist and nurses assisted mothers of children with SID to understand their children's condition through health education and counselling given to them.

It is evident from the following quotation:

*P10: I was assisted by a psychologist referred to me. During her hospital appointment social workers, a psychologist and a dietician assisted me with health education, and I managed to accept my child's condition.*

*P11: I was assisted by nurses who were always giving me information regarding my child's condition. And with that information, I started to accept my child.*

#### **4.3.6.3 Sub-theme 6.3: External social support**

The findings of the study indicated that some mothers of children with SID were assisted by their siblings and their mothers when they were away from their children by raising and looking after their children. Most mothers of children with SID they received support from their family members to help them cope with their children's situation.

It is evident from the following quotation:

*P5: The difficult times I had is when I was away from my child due to work, I am working far away from my child, and I left him with my mother, and I wish I can be there for my child but not saying that my mother is not taking care of him. That work takes me away from my child and I spent less time with my child I wish I can have had more time to spend with him seeing him develop.*

*P7: The only support I have was from my parents and my siblings in the care of my child.*

#### **4.3.6.4 Sub-theme 6.4: External financial support**

The findings of the study indicated that children with SID get grant money which helps their mothers to take care of them using their grant money. This is supported by all mothers using their children's grant money to pay for their school transport. *It is evident from the following quotation:*

*P3: My child is getting a grant I use that money to buy Christmas clothes*

*P4: My child is getting grant and with that grant I am able to take care of her I am able to pay school fee with the money.*

*P4: we are using her grant money to pay her transport.*

*P6: My child is getting grant and we are using his grant money to pay transport sometimes if the money is not enough his father pays his transport.*

*P8: My child is getting grant since I took him to special school, at school they told me to take the child to doctor who gave me a letter to go an enrol the child for grant because he was getting R350, so at special school and doctor's letter helped me because my child now is getting grant same as pensioner. That money is helping me to pay school fee and transport.*

#### **4.3.7 THEME 7: MOTHERS' RECOMMENDATIONS FOR PARTNERS' SUPPORT WITH A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

The findings of the study indicates that mothers of children with SID they recommend health professionals to assist them together with their partners to



accept their children's condition. Mothers' recommendations for partners' support with a child with a severe intellectual disability have two sub-themes namely: Recommendations for informational support and Recommendations for coping strategies

#### **4.3.7.1 Sub-theme 7.1: Recommendations for informational support**

The findings of the study indicate that mothers of children with SID seek assistance from health care workers to give them and their partner's with health education concerning their children's condition. This is supported by the findings of the study whereby mothers of children with SID says nurses and psychologist must give them and their partner's health education and counselling concerning their children's condition.

It is evident from the following quotation:

A 51 year old mother of 08 year old girl suggested that health care workers especially nurses to do home visits to educate them together with their partners about their children's condition (specially to educate their partners) so that they can have knowledge regarding their children's condition. As evidenced by: *"The key is for nurses to talk with those men to assist their partners by giving them health education. I am lucky because I get support from my partner and we treat our child like a normal child. Again, if possible, you nurses can do home visits like yourself and educate men about the condition of the child and on how to assist their partners with those children because other women are the ones who are faced with the care of their children alone"* P1.

Other participants also suggested similar recommendation *"I think if my partner can get health education about the child's condition from nurses and Doctors, I think it will assist him, my brother I mean a proper health education I think he can understand the child's condition"* P3.

Workshops and awareness regarding SID were also recommended by other participants *"Ohhh... because I realised that many people lack knowledge about disability conditions so workshops are needed concerning the conditions where parents who have this kind of children may come together and share their*

*knowledge and experiences. For our partners, men need people like you nurses to do a home visit and educate our partners about this condition” P6*

*P7: I think the way he is acting; he lacks knowledge maybe if he could get health education regarding mental retardation and other mental conditions from a nurse maybe he could be able to understand and be able to provide the support.*

*P8: They must go and speak to the psychologist he will help because he helped me and my partner and through the psychologist, he accepted the child. A Psychologist in his education told my partner to tolerate the child and he had him very well*

*P10: I think we must attend clinic appointments with our partners so that nurses can give us health education together concerning our children’s condition so that our partners can here and learner.*

*P11: I think as women we must voice out our problems so that we can get medical help from a psychologist, which will benefit our children. I think if we can get workshops and imbizo whereby people give us health talk about this mental condition of our children together with our partners.*

#### **4.3.7.2 Sb-theme 7.2: Recommendations for coping strategies**

The study's findings indicated that mothers of children with SID recommend that if their partners can get employment this can help them in the care of their children with SID. Most mothers of children with SID recommended that they and their partners assist each other in the care of their children with SID as this will make their families happy. It was further recommended that as partners, and parents to this child with SID, they must assist each other in the care of their child.

It is evident from the following quotation:

*P1: If partners assist each other in the care of their child they will be happy in the family because you can see our children are helpless and heart-breaking, so they need our love and to accept them from both of us.*

*P3: In my opinion, if we can have a family meeting and talk about that issue and maybe we can get support from my partner, I think it can help us me and my child.*

*P4: If my partner can get a job even if he can get a piece job that one can help him and us because he can be able to provide for us for example, he can buy a cake for her child during her birthday and able to take care of her child like other fathers because if he is working month end, he will be paid.*

*P5: Those that are not supported must involve their partners and try to make them understand their child's condition. As women, we are the ones who are attached to our children, and we spend most of our time with them if we discover something in involving our partner so that he can learn and develop an interest in the care of the child*

#### **4.4 DISCUSSION OF THE FINDINGS**

The discussion of the research findings on mothers' experiences of children with a severe intellectual disability regarding partner support in the Polokwane and Lepelle-Nkumpi municipalities of Capricorn District, Limpopo Province are presented below. The presentation of the research results focuses on mothers' perceptions of the child's disabilities, mothers' initial experiences of having a child with a severe intellectual disability, mothers' experiences of partners' support with a child with a severe intellectual disability, mothers' challenging experiences of partners' support with a child with a severe intellectual disability, mothers' experiences of caregiver burden related to partners' support, mothers' experiences of coping with caregiver burden related to partner support and mothers' recommendations for partners' support with a child with a severe intellectual disability.

##### **4.4.1 THEME 1: MOTHERS' PERCEPTIONS OF THE CHILD'S DISABILITIES**

A study conducted in Indonesia by Junaidi and Dewantoro (2020) on Parents' Perceptions of Children with Disabilities indicates that mothers' perceptions of children with disabilities determine how mothers educate and care for the child and also mother's acceptance of children affects children's development, social behaviour skills and adaptability. For the mothers' perception of the child with a disability to be understood the following sub-theme, physical and mental disability were discussed.

#### **4.4.1.1 SUB-THEME 1.1: Physical and mental disability**

The findings of the study indicates that mothers had different understanding regarding their children's conditions. Some mothers seem not to have adequate knowledge regarding their children's conditions, as they described their children as slow learners because they were never informed about the condition of their children. Two of the participants expressed that they are not sure of their children's disabilities. Their understanding of disabilities was limited. The study is similar to the one conducted in Sekhukhune district Limpopo province which indicated that parents' understanding about their children's disability was surprising. All the parents did not understand their children's disabilities well. They provided a general view about their understanding of disability (Tigere & Makhubele, 2019).

The participants further indicated that despite being consulted by the psychologist but they were never informed about their children condition. One mother expressed that she discovered her child condition after reading the psychologist report. The National Best Practice Guidelines in Europe (2015) stated that mothers who are not informed about their children's disability causes additional stress at what is likely to be a difficult time. When mothers are informed about their children's conditions there will be an improved outcomes through the implementation of best practice; and improved support, guidance, education and training for professionals in the important and sensitive task of delivering this news.

Some of the mothers in this study further stated that some children were born like that and in some the disability was discovered while they were growing. All participants in this study were able to describe their children's symptoms and pattern of behaviour. These include the delayed milestones, inability to walk, talk or write, and inability to adapt or understands the surroundings and poor concentration. The study conducted by Ntinda & Hlanze (2015) also reported that children with intellectual disability were also completely dependent on the caregiver. There are things which the children cannot do for themselves which they rely on their parents and caregivers for helping them.

Most of the participants expressed that their children's condition was discovered at the preschool by the teachers and referred them to the health institutions for further interventions. After seeking help from the health institutions, they were informed about their children's conditions. Some indicated that their children found to be suffering from Down syndrome, autism, HIV which contribute to their severe intellectual disability. According to the study conducted in the Netherlands by Kruithof, Willems, van Etten-Jamaludin & Olsman (2019) on the parent's knowledge of their children with profound intellectual and multiple disabilities stated that mothers' knowledge of their children with severe intellectual disabilities is seen as crucial in the physical and mental support and care of their children.

Other parents found not to be surprised by the diagnosis of their children as they were expecting after discovering that their children had the delayed milestones and some had history of disability in their families. The results are similar to the study conducted in Swaziland by Ntinda & Hlanze (2015) which stated that some of the children were born with the disability, in some it is hereditary and in some it was discovered at around age one

#### **4.4.2 THEME 2: MOTHER'S INITIAL EXPERIENCES OF HAVING A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

Mothers of children with a severe intellectual disability experience stress caused by challenges that come from having the child's disability, those challenges affect the mothers' emotionally and physically well-being (Chauke, Poggenpoel, Myburgh & Ntshingila, 2021). Mothers' initial experiences of having a child with a severe intellectual disability were discussed under the following sub-themes: Emotional experiences, Challenges to accepting reality and coping through acceptance.

##### **4.4.2.1 Sub-theme 2.1 Emotional experiences**

The findings of the study reported that some mothers of children with SID reported that they became very emotional after delivering children with SID. The emotional experience include crying and being very sad after the delivery of their children with SID. The findings of the study were similar to the study done by Oti-Boadi (2017) on exploring the lived experiences of mothers of children with

intellectual disabilities in Ghana, argued that raising children with SID creates enormous psychological challenges often expressed as depression, anxiety, and somatic symptoms for mothers.

Some mothers explained that when told that their children were having SID their emotion became worse, became very emotional because they were not expecting to deliver children with SID. Some reported that it became worse when told that their children will not be able to do basic things like bathing, feeding themselves, writing and even talking. The finding of the study was supported by study done by Oti-Boadi (2017) who stated that the daily care of a child with SID is demanding as the mother has to bath, dress, feed and nurture the child which can lead to long- term burdens that are stress and fatigue for the mother. The study conducted by Sairanen, Lappalainen, Lappalainen, Kaipainen, Carlstedt, Anclair, and Hiltunen, (2019) showed that the child's functional disability can increase parents' worries and stress in everyday life. This can lead into chronic stress reaction and burnout syndrome.

Some mothers and their partners of children with SID reported that they even asked themselves what they have done in this world to end up having children with SID. Other mother reported that during pregnancy his partner was supportive but after the delivery of their child, he stopped supporting her and their child, he lost hope on them. The finding of the study is similar to the study done by Carpenter and Egerson (2009) said that when mothers asking their partners to take care of their children with SID their partners always blamed their mothers for giving birth to children with SID.

One mother together with his partner reported that they were scarred at the beginning because their child was unable to talk, she was just using sign language when she needs something but now the child speech is improved, and she can speak. According to Moorcroft, Scarinci, & Meyer, (2019) stated that children with complex communication needs are not consistently accepted by parents.

Therefore, parents of children with a SID could benefit from treatments that provide them tools to handle difficult inner experiences that are evoked when facing challenges and hardships related to parenting a child with SID (Sairanen et al., 2019).

#### **4.4.2.2 Sub-theme 2.2: Challenges to accepting the reality**

The study findings revealed that mothers of children with SID failed to accept their children's conditions when told for the first time. This finding is similar to the study done at Saudi Arabia by Aldosari and Pufpaff (2014), they stated that mothers' first reaction to the birth of their children with SID is often a combination of hopelessness, loss and resentment and this feeling can be an obstacle for mothers to accepting their children. One mother who is having two children one with SID and other one without SID, she sometimes fails to understand why she is having different children, the other one is normal and the other one is having SID, and that issue makes her to feel more pains. Some mothers of children with SID thought having a child who suffered from SID was God's punishment. The findings agreed with Kumar and Panday (2019)'s findings stated that the parents wonder if they did something wrong, during the course of the pregnancy or after birth, while taking care of the child. They wonder if God is punishing them for their sins.

The intellectual disability of some children was reported to have been discovered at the preschool by the teachers. Mothers reported having an inability to accept the condition of their children revealed to them in the preschool. Teachers were blamed that they are unable to teach, they are not good teachers, and they hate their children. Few mothers thought of taking their children from one school to another. Teachers referred mothers to the hospital for the children's examination, counselling, and support in order to deal with the denial. The findings of the study are in agreement with Sherbini, Ahmed and Mohammed (2019)'s findings, they stated that nursing as a family-orientated prefinals involves supporting mothers of children with SID to gain an awareness of their roles and to cope appropriately with the challenges facing them.

#### **4.4.2.3 Sub-theme 2.3: Coping through acceptance**

Coping usually involves adjusting to or tolerating negative events or realities while you try to keep your positive self-image and emotional equilibrium (Cleveland, 2022). The findings of the study showed that mothers of children with SID accepted their child's conditions as they gave birth to them. Some mothers of children with SID they identified the disability before the diagnosis as they saw that their children had delayed milestones, after the diagnosis they accepted their child as a gift from God. Two mothers of children with SID reported that their partners accepted their children with SID as a gift from God and their relationship didn't change due to the birth of their children, they continued with their lives as before the birth of their children. The findings of the study were supported by Dura-Vila and Dein (2010), stated that partners use their religious as a way to make sense of why SID has happened to their children and to come to an understanding about themselves and their children's disability in a religious frame work. The birth may evoke positive attributions such as the child with SID is a gift from God.

Some conditions of some children were revealed by preschool teachers, hospital and psychologist that the mothers were referred to. Some mothers of children with SID reported that acceptance came after comparing the developmental milestones of their children with severe intellectual disabled with other children and through counselling. Some mothers reported that they accepted their children's condition as in their family they do have children with SID so it was not a new condition in their family. The findings of the study were supported by a study conducted in the United States by Kandel and Merrick (2007) on the child with a disability: parental acceptance, management, and coping, stated that mothers that accept their children with SID were defined as being in a state of balance between recognition of the children's limitation and seeking to compensate for this limitation.



#### **4.4.3 THEME 3: MOTHERS' EXPERIENCES OF PARTNERS' SUPPORT WITH A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

Mothers' experiences of partners' support with a child with a severe intellectual disability were discussed with the following sub-themes, acceptance of the child, involvement, and interest in the child, caring about and loving the child, positive relationship with the child, emotional support through encouragement, instrumental support through sharing supervision and caring role, informational support, and financial support.

##### **4.4.3.1 Sub-theme 3.1: Acceptance of the child**

The findings of the study showed that partners of mothers of children with SID accepted their children's conditions, as some mothers reported that their partners were proud of their children as they were walking with them around and some took them to parks while others took them for a long drive. The findings of the study are in agreement with the findings of Purba and Simanjuntak (2020) on fathers' acceptance and rejection of children with disability revealed that partners take the role of parenting their children with SID after accepting the fact of having a child with SID. Partners who accepted their children with SID will share a focus on parenting, but the focus is stronger on the child with SID than on other children. Results of the study conducted by Purba, and Simanjuntak, (2021) showed that acceptance of the father with a sincere heart helps the development of intellectual disabled children. Initially, there was rejection, because they were ashamed of having a mentally retarded child that the mother took the role of parenting without the support of the father. The father takes the role of parenting after accepting the fact of having an intellectual disabilities child.

##### **4.4.3.2 Sub-theme 3.2: Involvement and interest in the child**

The findings of the study indicated that some partners were involved and interested in the care of their children with SID, as some mothers reported that the way their partners were involved and interested in their children with SID, they were always asking for the hospital feedback of their children if they didn't manage to go with them to the hospital. Some mothers reported that their partners sometimes took their children to the hospital by themselves. Mothers of children with SID revealed that their partner assisted them with school work. The

findings were supported by Sato and Araki (2021) in the study on fathers 'involvement in rearing children with profound intellectual and multiple disabilities stated that partners improved their self-confidence in childrearing by discussing and sharing about their children's conditions and caregiving approaches with the mothers of their children with SID. Furthermore, Sato and Araki (2021) argued that partners' experience of being acknowledged and trusted by mothers of their children with SID with childrearing motivated them and enhanced their involvement.

#### **4.4.3.3 Sub-them 3.3: Caring about and loving the child**

The findings of the study indicated that partners of children with SID were taking care of their children and showing them love. From the study, mothers reported that their partners showed love and care to their children as they were always remembering their children's birthdays and buying cakes and doing parties for them. Some mothers reported that their partners the way they loved their children they were playing with them when they were busy with household duties. This was supported by a study done by Kandel and Merrick (2007) in the United States on the child with a disability: parental acceptance: management and coping, which stated that the birth of a child with SID requires partners to love their significant child, who is deprived of the ability to grant a feeling of achievement. Furthermore, Kandel and Merrick (2007) argued that the accepting partners are able to provide love to their child with SID, with no feelings of rejection and over-protection.

According to a study conducted in parents of children with autism it showed that parents who were more able to accept their child's diagnosis and to see things from their child's perspective were more likely to also be attuned during play interactions with their children (Di Renzo, Guerriero, Zavattini, Petrillo, Racinaro, & Bianchi di Castelbianco, 2020).

#### **4.4.3.4 Sub-theme 3.4: A positive relationship with the child**

The findings of the study showed that partners have a positive relationship with their children with SID as they gave their children love, support, and encouragement by assisting them with basic needs. Some mothers of children with SID reported that their partners had effective communication with their children as some of their children were using sign language to communicate everything they wanted and their partners were able to understand their children well. If the child need food will point to the kitchen and his father will prepare food for her without any problems. The findings of the study are similar to the findings of Davys, Mitchell, and Martin (2016) in their study on fathers of people with intellectual disabilities: a review of literature in Manchester found that some fathers were very involved in the day care of their children as they worry about their children with SID and want the best for them, and they took the main carer roles in their family to look after their children.

Some partners showed their positive relationship with their children by playing with them and the way their children we getting love from them they were always next to their fathers. One of the partners of mothers of children with SID showed his positive relationship with his child by assisting him with basic things, assisting him with school work teaching him how to hold pencil and write and assisting him with hygiene teaching him how to bath. The findings of the study were similar to the study conducted by Davys, Mitchell, and Martin (2016) reported that fathers were providing provision support roles to their partners and their children providing care in the home and advocacy and they were source finder roles as fathers wanted to provide a stable and caring environment for their children with SID.

#### **4.4.3.5 Sub-theme 3.5: Emotional support through encouragement**

The findings of the study revealed that mothers of children with SID were getting emotional support and encouragement from their partners about their children with SID. Some mothers indicated that when they were down and emotional about their children, their partners were always there to give them emotional support and words of encouragement. Some mothers reported that their partners

were always uplifting their emotions by saying to them that, this problem is everywhere and, in every family, and you were not the first person to have a child with a severe intellectual disability. The findings of the study were supported by a study done in Stellenbosch by Elna and Abraham (2020) on resilience characteristics of families with children with severe or profound intellectual disability, argued that support from within the family unit was deemed important by all the participating families as mothers of children with SID mentioned family members, their partners who played a valuable role in family's adaptation process in accepting their children as mothers of children with SID indicated that they supported each other as partners.

#### **4.4.3.6 Sub-theme 3.6: Instrumental support through sharing supervision and caring role**

The findings of the study revealed that most mothers of children with SID and their partners were sharing supervision and caring role on their children with SID as most mothers of children with SID stated that when they were not home their partners were looking after their children. Some mothers reported that when they were cleaning the house and going to the societies their partners look after their children. Mothers of children with SID stated that their partners were always accompanying them and their children to hospital for appointments and sometimes when they were not around to take their children to hospital for appointments their partners took their children to the hospital by themselves.

Some partners were also reminding their mothers of their children with SID about hospital appointments. A study done by Oti-Boadi (2017) on exploring the life experiences of mothers of children with SID in Ghana was similar to the findings of the study as he stated that 70% of mothers reported that they had support from their partners and this assisted them in sustaining their mental health as 3% of mothers reported that their partners helped a lot because when mothers were unable to take their SID children to school, hospital they took their children to school, hospital and even at home help with taking care of their children.

Mothers of children with SID reported that some of their partners took over on the basic needs of their children as some of their partners assisted with personal hygiene of their children. Some mothers of children with SID stated that their partners stopped them to bath their children and took over as some of their children were boys in their puberty stage and mothers were struggling, having stress when bating them. The findings agreed with Sherbini, Ahmed and Mohammed (2019)'s findings, they revealed that the present of child with SID in the family becomes a source of stress so the support from others family members helps in reducing this stress. The partner support is an important factor in reducing the stress as father was seeing to reduce the stress on the mother by taking the role of bathing his male child.

#### **4.4.3.7 Sub-theme 3.7: Informational support**

The findings of the study showed that mothers of children with SID received informational support from their partners and their family. Some mothers stated that their partners were searching for information about their children, and they shared the information they got with them so that they can have knowledge regarding their children's condition (SID). Some mother reported that his partner if hears some information regarding SID, he calls her and explains everything he had to her.

Some mothers of children with SID reported that they received informational support from their family members as their family members advised them to take their children to the hospital for assessment and to find special schools for their children's they saw that their children had a disability. The findings of the study were supported by a study done in Stellenbosch by Durr and Greeff (2020) indicated that support from within the family unit by partners was important as participants said they were working together with their partners to take care of their children with SID and they also received assisted from extended family and that assistance gave them a break to have time for themselves.

#### **4.4.3.8 Sub-theme 3.8: Financial support**

The findings of the study showed that most partners of mothers of children with SID were being supported financially. Most of the mothers stated that their partners gave them money to buy school uniforms, pay for transport, pay school fees and even transport money for their children's hospital check-ups. Mothers of children with SID stated that their partner were giving them money to buy Christmas clothes for their children when they were back from their piece job.

Some mother reported that she was unemployed and before his child get grant his partner was doing everything for them with his money. This finding of the study was similar to the study done by Sahay, Prakash, Khaique and Kumar (2013) on parents of intellectually disabled children: a study of their needs and expectations stated that a financial need is about paying for basic expenses, paying for special equipment, paying for therapy, day-care centres and paying for a babysitter which was done by their partners.

#### **4.4.4 THEME 4: MOTHERS' CHALLENGING EXPERIENCES OF PARTNERS' SUPPORT WITH A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

The findings of the study indicate that some partners of mothers of children with SID do not give mothers support as they reject and don't accept their children while other partners were giving them support. Mothers' challenging experiences of partners' support with a child with a severe intellectual disability were discussed under the following sub-theme, partners' challenges in accepting the child, partners' lack of emotional support (uninvolved and distant), partners' lack of instrumental support, parenting challenges, marital relationship challenges and financial challenges

##### **4.4.4.1 Sub-theme 4.1: Partners' challenges to accept the child**

The findings of the study showed that most partners of mothers of children with SID were having difficulties to accept their children born with SID. Mothers stated that most of their partners after the announcement of their children's diagnosis, most of their partners stopped supporting them, started to reject their children

and some disappeared. Purba and Simanjuntak (2020) on father's acceptance and rejection of children with disabilities supported the findings of the study by indicating that in their study initially there was a rejection of children with SID by their partners because they were ashamed of having children with SID and mothers took the role of parenting without the support of their partners. Discovering that the child has SID is a life-changing event for parents that presents them with many challenges. They have to deal with the negative emotions brought about by the diagnosis, such as despair, sadness, denial, anger, and self-blame (Juvini, Sadeg, Julien-Sweerts, & Zebdi, 2022).

Some partners of mothers of children with SID together with their family members accused the mothers that their children were basted children as in their families they don't deliver disabilities children. The findings of the study are similar to the findings of Sherbini, Ahmed and Mohammed (2019), revealed that sometimes relatives especially mother-in-law aunt and uncles are considered as the weapons that hit the mother for delivering a child with SID, the mother-in-law sometimes ask her son to remarry to have a healthy child.

Mothers of children with SID revealed that most of the partners the way they didn't accept their children they were shy to walk on the street with them, shy to talk about them with their friends and fail to take them to their family gatherings. The study was supported by study done by Kumar and Panday (2019) stated that many parents might feel that a child with SID is something to be ashamed of and cannot be allowed out of the house. Neighbours, relatives or others might make cruel remarks about the child and parents might feel isolated and without support.

#### **4.4.4.2 Sub-theme 4.2: Partners' lack of emotional support (uninvolved and distant)**

The findings of the study indicated that partners of mothers of children with SID distanced themselves from the mothers of their children after knowing their children's conditions and knowing that the conditions were not reversible. Some mothers stated that the support they received from their partners during pregnancy disappeared after the delivery of their children with SID. The findings of the study were similar to the study done by Bostrom and Broberg (2014) a

longitudinal study on fathers of children with SID, revealed that fathers of children with SID were less involved in the caring of the children with SID, unlike mothers. Partners continue with their paid work while mothers increase their involvement in caring for their children. Furthermore, partners focus more on the outside world while mothers pay closer attention to the day-to-day care of their SID children.

Some mothers reported that their partners were avoiding them at the house, leaving early in the morning and coming back home late and some stopped supporting them after the birth of their children. The findings of the study were supported by the study done by Jessica and Rhodes (2018) stated that mothers of children with SID were in single parents 'households as their partners were no longer in contact with them, providing little physical and emotional support.

#### **4.4.4.3 Sub-theme 4.3: Partners 'lack of instrumental support**

The findings of the study indicate that most partners of mothers of children with SID did not provide support to the mothers regarding care of their children. Some mothers in the study stated that their partners didn't accompany them to the hospital for their children's visits and mothers were also responsible to take care of their children in the house without the assist of their partners. Most mothers reported they went to different visit to different health workers alone without their partners as their partners distanced themselves from them.

The findings of the study were similar to the study conducted by Budak, Kucuk and Civelek (2018) on the study of life experiences of mothers of children with an intellectual disability: A qualitative study in Turkey stated that mothers reported that when they learned the diagnosis, their partners had more difficulties in accepting the situation than mothers did this result in the partner not providing sufficient support for the care of the child. Some mothers in the study done by Carpenter and Egerson (2007) said that when mothers ask their partners to take care of their child with SID, the partner always blames the mothers for giving birth to a child with SID.



#### **4.4.4.4 Sub-theme 4.4: Parenting challenges**

The findings of the study indicated that mothers of children with SID and their partners were having disagreement on how to parent their children with SID. Most of the partners of mothers of children with SID they wanted to treat their children with SID as like normal children, wanted them to do things as normal children and sometimes were hard on them if they failed to do so. Then their mothers were sometimes unhappy with the treatment and became angry. The findings of the study were supported by the study done by Francina, Tintu and Venishya (2018) on challenges of parents with two intellectual disabled children in Kerala, stated that parenting style and parenting levels of care of children with SID by mothers indicated that mothers tend to use a more permissive form of parenting in comparison to the partner (fathers) and this caused a problem with regard to the care of their children.

Another mother of a child with SID report that his partner called his family and disclosed their child's diagnoses and she was not happy with the discloser at first thinking that his partner is exposing her child but when time goes on, she realised that his partner was assisting them because at some point his family were assisting them in the care of their children when they were not around.

#### **4.4.4.5 Sub-theme 4.5: Marital relationship challenges**

The findings of the study revealed that some of the relationships between mothers of children with SID and their partners changed after the delivery of their children with SID. Some of their partners started to blame their mothers of children with SID for delivering children with SID and some started to reject their children and named them as basted children. The findings of the study were supported by Dura-Vila, Dein and Hodes (2010) they argued that the United Kingdom culture's perceived cause of their children's SID could be attributed to the unreliability of the partner, for example, attributed to innate inferiority of the mother's bad sexual practices and wrongdoing during pregnancy.

Other mother reported that his partner after realising that his child is having SID, life in the house was not good and his partner ended up filing divorce. The findings of the study were in agreement with the study done by Sobsey (2009)

on marital stability and marital satisfaction in families of children with disabilities, revealed that marriage of partners of children with SID had often been portrayed as difficult, dysfunctional, and particularly likely to end in divorce.

#### **4.4.4.6 Sub-theme 4.6: Financial challenges**

The findings of the study indicated that some partners of mothers of children with SID were unemployed and others lost their employment, so they were unable to provide for their children with SID financially. The findings of the study were supported by Saunders, Tilford, Fussell, Schulz and Kuo (2016) on the financial and employment impact of intellectual disability on families of children with autism, revealed that partners with children with SID may experience significant financial and employment burden compared to partners without children with SID as the cost of caring for children with SID during his or her lifetime has been estimated to 1.4 million in the United States. Study done by Oti-Boadi (2017) in Ghana was similar to the findings of the study as Oti-Boadi (2017) stated that having a child with SID may be associated with personal and financial adjustment and adaption to the new role of meeting the unique needs of the children.

Other mother stated that his partner was very supportive to them but financially was not due to job loss and that issue was stressing the mother as sometimes they were borrowing transport money to take their child for hospital visit. The findings of the study were similar to study conducted by Twala, Ntinda and Hlanza (2015) in the study of lived experiences of parents of children with disability in Swaziland, found that raising children with SID were expensive because partners had to buy medical equipment and supplies such as wheelchair and had to pay for medical care, private education, learning equipment and specialized transportations.

Another mother of a child with SID reported that she was struggling financially even though she was working because she was having five children including his child with SID and she has to take care of them all. Sometimes it was difficult because his partner was not supportive, he was taking her bank cards and go

spent the money somewhere else and that made her children to suffer as she was forced to remove his child from school hostel due to lack of finances.

#### **4.4.5 THEME 5: MOTHERS' EXPERIENCES OF CAREGIVER BURDEN RELATED TO PARTNERS' SUPPORT**

Mothers' experiences of caregiver burden related to partners' support showed that mothers of children with SID have strains in the care of their children with SID, this was discussed under the following sub-themes, instrumental burden, and financial burden.

##### **4.4.5.1 Sub-theme 5.1: Instrumental burden**

The findings of the study indicated that mothers of children with SID had to take care of their children as most of their partners were not interested in the care of their children. Most mothers stated that the care of their children was their burden as they were taking their children to hospital appointments alone some attended speech therapies and physiotherapies alone when their partners were sitting at home doing nothing. The findings of the study were supported by the study done in Turkey by Gurhopur (2017) on family burden among parents of children with intellectual disabilities, which stated that partners who do not display the same level of coping for their children with SID, those partners felt that they were not supported by their mothers of their children with SID and those partners felt emotions such as anger, annoyed and discouraged then mothers undertake the main responsibility to provide care for their children.

Another mother reported that she had difficulties in going to work, funerals, societies and shopping because his partner refuses to look after their child, she had to hire someone to look after their child. The findings of the study agreed with Amikile and Outwater (2012)'s findings stated that mothers of children with SID in United Kingdom reported economical challenges as their children interfere with various activities such as business and extra expenses associated with illness and mothers are no longer able to leave their children to work their focus is on their child.

Other mother who stated that she was pregnant with second born but his partner didn't care as she was still responsible for the care of their child and the household duties. She has to bath the child and again take the child to the hospital for appointments without his partner's assistances and that was too much on her and exhaustion. The findings agreed with Nurullah (2013)'s findings who found that mothers of children with developmental disabilities can experience negative feelings as stress, burden, sorrows and physical exhaustion.

#### **4.4.5.2 Sub-theme 5.2: Financial burden**

The findings of the study indicated that some mothers of children with SID were not financially supported by their partners. Some mothers stated that they were the ones who were buying school uniforms, paid school fees, and transport for their children as their partners were not supportive and other told them that they will never support them and their children financially. The findings of the study were supported by the study done by Shahat and Greco (2021) in Landon on the economic cost of childhood with disability: a literature review stated that childhood of children with SID can bankrupt the household because of the direct extra cost of caring for their disabilities which are health care, wheelchair, and childcare.

#### **4.4.6 THEME 6: MOTHERS' EXPERIENCES OF COPING WITH CAREGIVER BURDEN RELATED TO PARTNER SUPPORT**

Mothers' experiences of coping with caregiver burden related to partner support were discussed under the following categories, internal coping (acceptance and spiritual coping), informational support, external social support, and external financial support.

##### **4.4.6.1 Sub-theme 6.1: Internal coping (acceptance and spiritual coping)**

The findings of the study revealed that some mothers used their religious beliefs to accept their children as they were always praying to God to give them strength to look after their children. Some mothers stated that they accepted their children's disabilities as a gift from God. The findings of the study were similar to

the study done by Dura-Vila and Dein (2010) on children with intellectual disability: parental beliefs and family life argue that most mothers may use their religion as a way to make sense of why SID has happened to their children and to come to an understanding about themselves and the children's disability in a religious framework. The birth may evoke positive attributions such as the child with SID was a gift from God.

#### **4.4.6.2 Sub-theme 6.2: Informational support**

The findings of the study indicated that health professionals were giving mothers of children with SID health education regarding their children's condition and with the education mothers received, mothers were able to accept their children's condition. Some mothers stated that health education that they received at hospitals from nurses, social workers psychologist and dieticians assisted them to accept their children. The findings of the study were supported by a study done by Douglas, Redley and Ottmann (2016) on the first year, the support needs of parents caring for a child with an intellectual disability, they argued that mothers of children with SID faced significant challenges during the first year of their children's life which is an important developmental period and provision of support by a health professional, particular nurses and midwives during the crucial period can impact on the maternal well-being and on the health and development outcomes of their children.

#### **4.4.6.3 Sub-theme 6.3: External social support**

The findings of the study indicated that some mothers of children with SID had support from their family members who assisted them in taking care of their children when they were away from their children. Some mothers reported that they left their children with their mothers and their siblings due to work, their mothers and their siblings were the ones who gave them support in the care of their children as compared to their partners.

The findings agreed with Upadhyaya and Havalappanavar (2008)'s findings revealed that none of the parents were having any problems with their grandparents and they were satisfied with their support on the care of their children. Again the findings of the study were supported by a study done by Francina, Tintu and Ivana (2018) the on challenges of parents with two

intellectual disabled children, argued that partners with greater social support showed positive parenting behaviour and again argued that support from parents and related family members have shown great influence in the well-being of mothers of children with SID.

#### **4.4.6.4 Sub-theme 6.4: External financial support**

The findings of the study revealed that most of children with SID were receiving grant. Most of mothers of children with SID stated that the grant money assisted them in the care of their children as they were able to pay school transport and buy school uniform for their children with SID. The findings of the study were supported by a study conducted in Durban by Sefotho, Ferreira and Lushozi (2021) on the quest for ongoing support by parents of learners with intellectual disabilities, stated that in South Africa people with disabilities receive monthly grants provided by the South African Social Security Agency (SASSA), they further explained that the South African social grants programs were introduced under the Department of Social Development to address the problem of poverty, more especially for the people who cannot afford to fend for themselves due to age or disabilities.

Sefotho, Ferreira and Lushozi (2021) reported that mothers of children with SID have been benefiting from the SASSA disability grant in support of their children. Again, the findings of the study were similar to the findings of the study done by Francina, Tintu and Ivana (2018) on challenges of parents with two intellectual disabled children they found that mothers of children with SID benefit from concrete services such as stipend programmes and respite care. Francina, Tintu and Ivana (2018) in their findings argued that partners rated the cash subsidy as helpful, improving their overall family life and ability to care for their children with SID and they were able to get more respite care and professional services due to the subsidy.

#### **4.4.7 THEME 7: MOTHERS' RECOMMENDATIONS FOR PARTNERS' SUPPORT WITH A CHILD WITH A SEVERE INTELLECTUAL DISABILITY**

The findings of the study indicate that most mothers of children with SID recommend health care professionals to assist them and their partners to accept their children's condition. Mothers' recommendations for partners' support with a child with a severe intellectual disability were discussed under the following sub-themes, recommendations for informational support and recommendations for coping strategies.

##### **4.4.7.1 Sub-theme 7.1: Recommendations for informational support**

The findings of the study indicated that most mothers of children with SID recommend health care to give their partners health education regarding their children's condition. Most of mothers recommend nurses to do home visit, to educate their partners with their children's condition and they believe through education their partners will support them in the care of their children. The findings of the study are similar to the study done in Turkey by Cavkaytar, Ceyhan, Adiguzel and Uysal (2012) on investigating education and support for families who have children with intellectual disabilities, showed that the informative counselling for partners' needs of knowledge, education reduces the concern and stress and help in their adjustment process to their children's conditions.

Cavkaytar, Ceyhan, Adiguzel and Uysal (2012) furthermore in their study argued that partners need to be informed about how they should cope with their children's behavioural problems and what kind of education they should offer their children. To fulfil this need of the partners Cavkaytar, Ceyhan, Adiguzel and Uysal (2012) said it was expected counsellors to offer behavioural management, teaching skills and services and sources of the programs that partners will apply at home.

Some mothers recommended workshops, awareness and imbizos where by a health professional can educate them, their partners and the community about the mental conditions (SID) while some mothers recommended psychological

counselling as his partner accepted his child after psychological counselling. The findings were similar to the study conducted by Sherbini, Ahmed and Mohammed (2019), stated that public education and awareness campaigns on mental health and needs of mentally disabled should be launched in all primary health care settings and paediatric hospital.

#### **4.4.7.2 Sub-theme 7.2: Recommendation for coping strategies**

The study's findings indicated that most mothers of children with SID recommended that if their partners can be employed, this will assist them to take care of their children financially. Most mothers stated that if their partners can get a job, they will be able to pay for their children's school fees and buy them cake during their birthdays. Other mothers recommended involving their partners in their children's care by always talking to them about their children's condition. The findings of the study were supported by a study done in India by Ganjiwale, Gnjiwale, Sharma and Mishra (2016) on the quality of life and coping strategies of caregivers of children with physical and mental disabilities they stated that the fact that partners support each other and share caretaking tasks and other housework equally was of major importance for their marital relationship and for their SID children.

#### **4.5 INTEGRATION OF THE THEORY AND FINDINGS**

The findings of the study in relation to the theory are presented. Lakey and Cohen theory focuses on social support and measurement (Lakey & Cohen, 2000). The theory was designed to inform the researcher when selecting measures of social support that social relation influences health and wellbeing.

**Table 4.2 schematic representation of the relationship between theories and findings of this study**



Main concepts of the framework	Description	Results
<p><b>Stress and coping perspective</b></p>	<p>According to this view, each Stressful circumstance places specific demands on the affected individual however support reduces the effects of stressful life events on health (Lakey, &amp; Cohen, 2000)</p> <p>Social support will be effective in promoting coping and reducing the effects of stress.</p>	<p><b>The stressful circumstance that places specific demands on the mothers were as follows:</b></p> <ul style="list-style-type: none"> <li>• The condition of their children</li> <li>• The physical and mental disability of the children such as delayed milestones, lack of speech, poor concentration and understanding, seizures, poor academic progress</li> <li>• Emotional distress such as crying</li> <li>• Feeling of being punished by God</li> <li>• Blaming teachers for their children's condition</li> <li>• Partners not accepting the children, some denied the children based on their condition</li> <li>• Rejection of the children with SID (Partners claiming that the children with SID are not theirs)</li> <li>• Partners refusing to go for counselling</li> <li>• Substance abuse by partners after the diagnosis has been revealed to them</li> <li>• Partners' challenges to accept the child</li> <li>• Partners' lack of emotional support (uninvolved and distant)</li> <li>• Partners' lack of instrumental support</li> <li>• Parenting challenges</li> <li>• Marital relationship challenges</li> </ul>

		<ul style="list-style-type: none"> <li>• Financial challenges - buying school uniforms, Christmas clothes and paying for the child's transport</li> <li>• Social isolation due to the burden of caring</li> </ul>
<b>Social constructionist perspective</b>	<p>Social constructions refer to the assumption that people's perceptions about the world do not reflect ultimate reality. Instead, people construct theories and concepts about the world that reflect their social context (Lakey, &amp; Cohen, 2000)</p> <p>This perspective emphasises the actual assistance provided by others during stress</p>	<p><b>The findings emphasise the actual assistance (Social support) provided to the mothers by others during stress</b></p> <ul style="list-style-type: none"> <li>• Support from the preschool teachers</li> <li>• Referral to the hospitals for counselling</li> <li>• Support from family members</li> <li>• Informational support from the health care providers</li> <li>• External social support (Church)</li> <li>• External financial support</li> </ul> <p>Some mothers received social support which has been of importance in promoting coping and reducing the effects of stress</p>
<b>The relationship perspective</b>	<p>A third perspective on social support conceptualises support as part of more generic relationship processes. These relationship qualities reflect neither actual help during times of stress nor beliefs</p>	<p><b>The relationship perspective was related to the support from the mother's partners which include the following:</b></p> <ul style="list-style-type: none"> <li>• Acceptance of the child</li> <li>• Involvement and interest in the child</li> <li>• Caring about and loving the child</li> </ul>

	about support per se (Lakey, & Cohen, 2000)	<ul style="list-style-type: none"> <li>• Positive relationship with the child</li> <li>• Emotional support through encouragement</li> <li>• Instrumental support through sharing supervision and caring role</li> <li>• Financial support</li> <li>• Informational support</li> </ul>
Companionship	Companionship involves "shared leisure and other activities that are undertaken primarily for the intrinsic goal of enjoyment" (Lakey, & Cohen, 2000)	<ul style="list-style-type: none"> <li>• After the birth of the child with SID other partners distanced themselves which affected the companionship between the mothers and their partners.</li> <li>• However, other partners were more involved and supported the mothers which enhance the companionship.</li> </ul>
Intimacy	Relationship satisfaction is defined as global, subjective evaluations of relationships and Intimacy is the "bonded, connected, and close feelings people have toward each other" (Lakey, & Cohen, 2000)	The intimacy between the mothers and their partners suffered after the birth of their children with SID specifically for those partners who rejected their own children because of disability, however, others reported more bond and connection with their partners.
Low social conflict	Low social conflict," includes criticism, breaking of promises, or fighting for limited resources (Lakey, & Cohen, 2000)	After the birth of the child with SID, some families experienced social conflict resulting in divorce

Table 4.2 above summaries the integration of the theory and the findings. The three main concepts of the theory were integrated with the findings. **Stress and coping perspective** were integrated with the stressful circumstance that places specific demands on the mothers. **Social constructionist perspective was integrated with the** actual assistance (social support) provided to the mothers by others during stress by the social network such as health workers, family members, preschool teachers and the church. **The relationship perspective** was integrated with the support that the mothers of children with SID receive from their partners.

#### 4.6 CONCLUSION

This chapter described and discussed the results, the themes and sub-themes, the discussion of the findings and the integration of the theory and findings. The next chapter will discuss the summary, recommendation, limitations, and conclusion of the study. The reality is that all the participants of the study were female, some were married, some not married and some divorced. Some mothers were staying with their partners on daily bases while others were not staying with their partners on daily bases due to work.

The study was done in Limpopo province in rural area which doesn't have enough developed facilities like special schools and health services that are suitable for children with SID. Support groups for mother and partners of children with SID in Limpopo province are not well established hence some partners of mothers of children with SID they don't have support from their partners as their partners might have lack of knowledge regarding SID condition.

Culturally in rural area children born with disabilities is seen as a sin and the sin is placed on the mother's side, mothers are being blamed by their partners and their families for delivering a child with SID. Their partners refused their children as basted child. Most partners of mothers of children with SID in Limpopo province are not working and they have difficulties is caring for their children as the care of a child with SID is expensive. South Africa government introduced

grant for people with disabilities, but the grant money is still not enough for the care of children with SID as their care are expensive.

## CHAPTER 5

### SUMMARY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

#### 5.1 INTRODUCTION

This chapter presents a summary of the research report, the limitations of the study, the conclusion that was drawn from the research findings and the themes and sub-themes in chapter 4. The recommendations are given to enable partners of mothers of children with SID to support them in the care of their children.

#### 5.2 RESTATEMENT OF THE OBJECTIVES

**The objectives of this study were:**

**Objective 1:**

**To explore and describe mothers' experiences of children with a severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province.**

These objectives were achieved in Chapters 1, 2, 3 and 4 of the study. In Chapter 1, an overview of the research study was given to familiarise readers with the introduction and background of the research that led to the formulation of the problem statement. The statement of the problem specifies the experiential observations that influenced the study. In Chapter 2, the literature review was presented throughout the study to guide the exploration of the existing literature. In Chapter 3, a qualitative explorative and descriptive design was applied in conducting this study. A non-probability purposive sampling technique was used to obtain twelve mothers of children with SID at three selected special schools as participants. Data were collected using structured one-on-one interviews. Data were analysed using Tesch's approach to data analysis. In Chapter 4, themes and sub-themes were presented and discussed.

## **Objective 2:**

### **To recommend measures to promote partner support for parents of children with severe intellectual disability**

This objective was achieved in Chapter 5, measures to promote partner support for parents of children with severe intellectual disability were recommended for each theme. The recommendation focused on management, practice, research, education, and training.

## **5.3 SUMMARY OF THE MAIN FINDINGS**

**The findings of the study are based on the following seven themes:**

### **5.3.1 Theme 1: Mother's perceptions of the child's disabilities**

Mothers reported that their children with SID have physical and mental disabilities. These include delayed milestones, impaired speech, poor concentration and understanding of instructions, poor performance at school, dependent on the caregiver, and some experienced seizures. The specific diagnosis for these children was HIV, Autism Spectrum Disorder, Down syndrome, learning disorders, and intellectual disability, however, all the children were classified under the severe intellectual disability level. The study found that the condition of these children was viewed as a stressful circumstance that places a demand specifically on the mother.

### **5.3.2 Theme 2: Mother's initial experiences of having a child with severe intellectual disability**

The study found that mothers found it difficult to accept their children's condition when told for the first time, as they have associated their children's condition with loss and punishment from God. Most mothers explained that they were emotional as they cried, felt sad, blamed the teachers, and were shocked by their children's condition. Few mothers accepted their children as a gift from God and did not have a problem with their children's condition. Mothers found to interpret their

children's situation differently perceived it as a threat or challenging while others perceive it as something they can cope with. The results align with the stress and coping theory by Lazarus and Folkman (1984) which states that how people interpret situations is important in determining the event stressfulness.

### **5.3.3 Theme 3: Mother's experiences of partner's support with a child with a severe intellectual disability**

The study revealed that the majority of mothers of children with SID receive support from their partners, this include partner looking after the children when mothers are not at home, partners accompanying them to the hospital for appointments and assisting them at home with basic needs by bathing and making food for their children. Most partners are proud of their children and remember their children's important dates (birthdays date). The social support theory that guided the study states that support reduces stressful life events' effects on an individual's health. Supportive actions are thought to enhance coping performance, meaning the support the partner provides to the mothers will enhance the coping performance.

### **5.3.4. Theme 4: Mother's challenge experiences of partner's support with a child with a severe intellectual disability**

The study's findings showed that other mothers lack partner support as their partners denied their children after knowing their condition. Some of the partners distanced themselves and stopped supporting the mothers. Most mothers reported that their relationship changed after the delivery of their children as their partners blamed them for delivering children with SID. The framework describes these as the social conflict which might affect individual self-esteem, psychological state, and health.

### **5.3.5. Theme 5: Mother's experiences of caregiver burden related to partner's support**



The study showed that mothers of children with SID had difficulties taking care of their children with SID as their partners were not interested in them. Most mothers responded by saying their partners are not providing them with money to pay for their children's school fees and transport and they are not taking care of their children when they are not at home. The findings relate to the relationship perspective of the coping and stress theory. These relationship qualities reflect neither actual help during the time of stress nor beliefs about support per se.

#### **5.3.6. Theme 6: Mother's experiences of coping with caregiver burden related to partner support**

The study revealed that mother of children with SID shared their experiences regarding the coping mechanism that they used to cope with their children with SID, this includes using religious beliefs, support from health care workers and their family members to cope with caregiver burden related to partner support. The coping and stress theory perceived those supportive behaviors as others promoting coping and reducing the effects of stress.

#### **5.3.7. Theme 7: Mother's recommendations for partner's support with a child with a severe intellectual disability**

The study showed that mothers of children with SID recommended health education to be given to their partners so that their partners can know about their children's condition. Most mothers seek assistance from healthcare workers, especially nurses, to give them and their partner health education about SID and for psychologists to assist them with counseling about their children's condition. Therefore, other mothers of children with SID recommended a workshop to be done about their children's condition and in that workshop to include their partners.

### **5.4 RECOMMENDATIONS**

The following recommendations are based on the seven themes that emerged during a one-on-one interview with the mothers of children with SID in the

Capricorn district in Limpopo province. The recommendations focus on promoting partner support, research, education, and training as illustrated in Table 5.1 below.

**Table 5.1: Recommendations**

Theme	Recommendations to promote partner support	Recommendation for educational and training	Recommendation for research
<p><b>Theme 1:</b> mother's perceptions of the child's disabilities</p>	<ul style="list-style-type: none"> <li>• It is essential for healthcare workers to provide knowledge about SID and other related conditions by educating both parents of the children with SID immediately after the diagnosis.</li> <li>• The health education should be continuous during a follow-up visit.</li> <li>• Both parents must be given pamphlets and encouraged to read online sources about SID.</li> <li>• Both parents should attend awareness on intellectual disabilities at the special</li> </ul>	<ul style="list-style-type: none"> <li>• Promotion of partner support for parents of children with disabilities should be emphasized when training Psychiatric nurses to encourage both parents to participate in caring for the children.</li> </ul>	<ul style="list-style-type: none"> <li>• Further research should be undertaken to assess the knowledge of parents regarding their children with SID condition</li> </ul>

	schools, health institutions or community		
<b>Theme 2:</b> Mother's initial experiences of having a child with severe intellectual disability.	<ul style="list-style-type: none"> <li>Professional nurses and psychologists should provide genetic counseling and family therapy to deal with the emotional part of the mothers and their partner's immediately after birth and throughout development as this explanation could assist them in accepting their children.</li> <li>The counselling given to the mothers and the partners should be specific and should emphasize the specific disabilities of their children and the management or care of</li> </ul>	<ul style="list-style-type: none"> <li>All professional nurses should receive training and in-service training on genetic counseling</li> </ul>	<ul style="list-style-type: none"> <li>Further research should be undertaken to assess the type of counselling or therapy provided to parents of children with SID.</li> </ul>

	<p>their children throughout their development</p> <ul style="list-style-type: none"> <li>• These might assist mothers and their partners to accept their children with SID and be able to care for them throughout development.</li> </ul>		
<p><b>Theme 3:</b> mother's experiences of partner's support with a child with a severe intellectual disability</p>	<ul style="list-style-type: none"> <li>• Mothers of children with SID and their partners need to do the following to promote support for each other:</li> <li>• Acceptance of the child's condition</li> <li>• Involvement and interest in the child</li> <li>• Caring about and loving the child</li> <li>• Positive relationship with the child</li> <li>• Emotional support through encouragement</li> </ul>	<ul style="list-style-type: none"> <li>• All professional nurses should provide parent training education</li> <li>• Professional nurses should receive in-service training on the establishment of support groups</li> </ul>	<ul style="list-style-type: none"> <li>• Further research should be undertaken on the education given to parents of children with SID to promote acceptance of their children's condition.</li> </ul>

	<ul style="list-style-type: none"> <li>• Sharing supervision and caring role</li> <li>• Informational support</li> <li>• Financial support</li> </ul>		
<b>Theme 4:</b> Mother's challenging experiences of partner's support with a child with a severe intellectual disability	<ul style="list-style-type: none"> <li>• Partners of mothers of children with SID need to do the following so that they can be able to provide support: by attending hospital appointments, attending psychologist and couple counselling together with their mothers of their children, this will assist them in having the same understanding on their children's condition</li> </ul>	<ul style="list-style-type: none"> <li>• All health care counsellors should receive in-service training on couple counselling</li> </ul>	<ul style="list-style-type: none"> <li>• Further research must be undertaken to assess couple counselling on children with SID</li> </ul>
<b>Theme 5:</b> mother's experiences of caregiver burden related to partner's support	<ul style="list-style-type: none"> <li>• To promote support to partners of children with SID, health care workers need to focus their attention on creating support systems as well as awareness of the importance of partners</li> </ul>	<ul style="list-style-type: none"> <li>• Professional nurses to use social and mass media to do awareness and campaigns about the importance of partner support for children with SID</li> </ul>	<ul style="list-style-type: none"> <li>• Further research should be undertaken to assess services available for partners of children with SID</li> </ul>

	involved in the care of their children with SID		
<b>Theme 6:</b> mothers' experiences of coping with caregiver burden related to partner support	<ul style="list-style-type: none"> <li>Partners of children with SID should receive the following support for them to cope with their children with SID: social support (support from family members), external financial support (grant money) and spiritual support</li> </ul>	<ul style="list-style-type: none"> <li>Healthcare workers to form support groups for partners of children with SID in order to share their experiences and their coping strategies with their children with SID</li> </ul>	<ul style="list-style-type: none"> <li>Further research should be undertaken to reinforce the coping strategies for partners of children with SID</li> </ul>
<b>Theme 7:</b> mothers' recommendations for partners' support with a child with a severe intellectual disability	<ul style="list-style-type: none"> <li>Health care workers need to give partners counseling immediately after the delivery of a child with SID and counseling should be continued until the development</li> </ul>	<ul style="list-style-type: none"> <li>To provide health care workers with a couple of counseling</li> </ul>	<ul style="list-style-type: none"> <li>Further research must be undertaken on family therapy to reinforce the knowledge of partners regarding their children with SID</li> </ul>

## **5.5 LIMITATION OF THE STUDY**

The study was conducted in three special schools at Lepelle-Nkumpi and Polokwane municipalities of Capricorn district of the Limpopo Province in South Africa. Therefore, the findings cannot be generalized to another special school in another province. Data was collected during the COVID-19 lockdown, which delayed getting permission to collect data as the schools were closed for a long time. After getting the permission to collect data, it was not allowed to gather the mothers at the school due to COVID-19 protocols, hence the researcher has to communicate with the mothers telephonically to request them to participate in the study. Data was collected at their home and the researcher had to travel from one village to the other. The facial expression could not be assessed thoroughly due to wearing the face mask.

## **5.6 CONCLUSION**

The study showed that mothers who receive partner support were coping well than those without the support from their partners. The stress level for mothers without partner support was reported to be high. To achieve the support of partners for mothers of children with SID, the healthcare workers, nurses, and doctors as the first healthcare workers to identify the disability after birth, should immediately inform the mothers and their partners about the child's disability and start with counseling immediately and continue with counselling throughout development. The doctors should refer the mothers of children with SID with their partners to psychologists for further counseling. Counselling is important as it will help the mothers of children with SID and their partners to accept their children at the beginning and raise them knowing their condition well and be able to support each other.



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## APENDIXES

### APPENDIX A: ENGLISH INTERVIEW GUIDE

#### Central question

- Kindly describe your experiences regarding the support that you receive from your partner when caring for your child with a severe intellectual disability

#### Probing question

- How did you and your partner feel for the first time when told that your child has severe intellectual disability
- How was the interaction between you and your partner after being told that your child has severe intellectual disability?
- Is your partner supportive in the care of your child?
- When was it difficult times for you to take care of your child?
- What do you think should be done to improve your partner's support?

## APPENDIX B: SEPEDI INTERVIEW GUIDE

### Potšišo kgolo

- Ke kgopela gore o hlaloše maitemogelo a gago mabapi le thekgo yeo o e humanago molekaneng wa gago mabapi le ngwana wa lena wago seitekanele.

### Potšišo tšago latelana

- Le ikwele bjang wena le molekani wa gago gele tsibišwa la mathomo gore ngwana wa lena gaa itekanela
- Ka morago gago tsibišwa gore ngwana wa lena gaa itekanela wena le molekani wa gago le ile la swarana bjang
- Molekani wa gago wago thekga thlokomelong ya ngwana
- Ke neng mo o kweleng gole boima hlokomelong ya ngwana wa gago
- Nagana gore goka dirwa eng mabapi lego nolofatša thekgo molekaneng wa gago.

**APPENDIX C: CONSENT FORM (ENGLISH)**

**DEPARTMENT OF NURSING SCIENCE ENGLISH CONSENT FORM**

**Statement concerning participation in a Clinical Research Project.**

**Name of the project/ study: experiences of mothers of children with severe intellectual disability regarding partner support in the Capricorn district, Limpopo province**

I have read the information and heard the aims and objectives of the proposed study and was provided with the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I understand that participation in this Study / Project is completely voluntary and that I may withdraw from it at any time and without supplying reasons.

I know that this Study / Project has been approved by the Turfloop Research Ethics Committee (TREC). I am fully aware that the results of this Study / Project will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

Any questions that I may have regarding the research or related matters, will be answered by the researcher/s.

I hereby give consent to participate in this Study / Project.

Signature of researched person.....Signature of researcher.....

Signed at..... this.....day of.....2020

Contact NO: 0720285659 / 0671802849

Email address: [lopzen@webmail.co.za](mailto:lopzen@webmail.co.za)

## APPENDIX D: CONSENT FORM (SEPEDI)

Setatamente mabapi le go tšea karolo ka go ya Dinyakišišo.

Leina la Dinyakišišo: Maitemogelo a bomme ba goba le bana ba gose intekanele mabapi le thekgo gotswa go balekani ba bona mo Tistiriking ya Capricorn, porofensing ya Limpopo

Ke kwele ka ga tshedimošo mabapi le maikemišetšo le morero wa dinyakišišo tšeo di šišintšwego gomme ke ile ka fiwa monyetla wa go botšiša dipotšišo gomme ka fiwa nako yeo e lekanego gore ke e naganišiše ka ga taba ye. Ke tloga ke kwešiša maikemišetšo le morero wa dinyakišišo tše gabotse. Ga se ka gapeletšwa go kgatha tema ka tsela efe goba efe.

Ke a kwešiša gore go kgatha tema Dinyakišišong tše ke ga boithaopo gomme nka tlogela go kgatha tema nakong efe goba efe ntle le gore ke fe mabaka.

Ke a tseba gore Dinyakišišo tše di dumeletšwe ke Turfloop Research Ethics Committee (TREC), Yunibesithi ya Limpopo (Khamphase ya Turfloop) le Kgoro ya tša Thuto. Ke tseba gabotse gore dipoelo tša Dinyakišišo tše di tla dirišetšwa merero ya saense gomme di ka phatlalatšwa. Ke dumelelana le se, ge fela bosephiri bja ka bo ka tiišetšwa.

Mo ke fa tumelelo ya go kgatha tema Dinyakišišong.

.....

Leina la moithaopi	Mosaeno wa moithaopi	goba mohlokamedi.
.....	.....	.....

Lefelo.	Tlhatse	Letšatšikgwedi.
---------	---------	-----------------

Setatamente ka Monyakišiši

Ke fana ka tshedimošo ka molomo le/goba yeo e ngwadilwego mabapi le Dinyakišišo tse Ke dumela go araba dipotšišo dife goba dife tša ka moso mabapi le Dinyakišišo ka bokgoni ka moo nka kgonago ka gona. Ke tla latela melao yeo e dumeletšwego.

.....

Leina la Monyakišiši	Mosaeno	LetšatšikgwediLefelo
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# APPENDIX E: PERMISSION LETTER TO CONDUCT THE STUDY DEPARTMENT OF EDUCATION



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

## DEPARTMENT OF EDUCATION

CONFIDENTIAL

Ref: 2/2/2 Enq: Makola MC Tel No: 015 290 9448 E-mail: [makolaMC@edu.limpopo.gov.za](mailto:makolaMC@edu.limpopo.gov.za)

**Makgoga MT**  
P O Box 460  
Jane Furse  
1085

### RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

1. The above bears reference.
2. The Department wishes to inform you that your request to conduct research has been approved. Topic of the research proposal: **"EXPERIENCE OF MOTHER OF CHILDREN WITH SEVERE INTELLECTUAL DISABILITY REGARDING PARTNER SUPPORT IN THE CAPRICORN DISTRICT, LIMPOPO PROVINCE"**
3. The following conditions should be considered:
  - 3.1 The research should not have any financial implications for Limpopo Department of Education.
  - 3.2 Arrangements should be made with the Circuit Office and the School concerned.
  - 3.3 The conduct of research should not in any way disrupt the academic programs at the schools.
  - 3.4 The research should not be conducted during the time of Examinations especially the fourth term.
  - 3.5 During the study, applicable research ethics should be adhered to; in particular the principle of voluntary participation (the people involved should be respected).

REQUEST FOR PERMISSION TO CONDUCT RESEARCH: MAKGOGA MT

Gnr. 113 Biccard & 24 Excelsior Street, POLOKWANE, 0700, Private Bag X9489, POLOKWANE, 0700  
Tel: 015 290 7600, Fax: 015 297 6920/4220/4494

*The heartland of southern Africa - development is about people!*

- 3.6 Upon completion of research study, the researcher shall share the final product of the research with the Department.
- 4 Furthermore, you are expected to produce this letter at Schools/ Offices where you intend conducting your research as an evidence that you are permitted to conduct the research.
- 5 The department appreciates the contribution that you wish to make and wishes you success in your investigation.

Best wishes.



**Dederen KO**  
**Head of Department**

06/07/2021  
**Date**

## APPENDIX F: ETHICAL CLEARANCE LETTER



**University of Limpopo**  
Department of Research Administration and Development  
Private Bag X1106, Sovenga, 0727, South Africa  
Tel: (015) 268 3935, Fax: (015) 268 2306, Email:  
makoetja.ramusi@ul.ac.za

**TURFLOOP RESEARCH ETHICS COMMITTEE**  
**ETHICS CLEARANCE CERTIFICATE**

**MEETING:** 24 March 2021

**PROJECT NUMBER:** TREC/52/2021: PG

**PROJECT:**

**Title:** Experiences of mothers of children with severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province  
**Researcher:** MT Makgoga  
**Supervisor:** Mrs GO Sumbane  
**Co-Supervisor/s:** Mr MO Mbombi  
**School:** Health Care Sciences  
**Degree:** Master of Nursing

**PROF P MASOKO**

**CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE**

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: REC-0310111-031

**Note:**

- i) This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.
- ii) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.
- iii) PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

## APPENDIX G: PERMISSION LETTER SPECIAL SCHOOL A



### BANA BA THARI SCHOOL FOR LEARNERS WITH INTELLECTUAL IMPAIRMENTS

Enq: Nkoana M.M.  
Cell: 081 468 5653/ 082 934 0164  
Email: [banabatharischool@yahoo.com](mailto:banabatharischool@yahoo.com)  
matebele.kgadi@gmail.com

PO BOX 638 638  
Sovenga  
0727

Emis No: 923242552

10 November 2021

Attention: Makgoga MT

P.O. BOX 460

JANE FURSE

1985

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT BANA BA THARI SCHOOL FOR LEARNERS  
WITH INTELLECTUAL IMPAIRMENTS.

1. The above matter bears reference:
2. Bana Ba Thari school for learners with intellectual impairments wishes to inform you that your request to conduct research has been approved by the stakeholders in the school. Topic of the research proposal: " **Experience of mother of children with severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province**".
3. The following conditions should be considered when conducting your research.
  - The research should not have any financial implications to the school and interviewees.
  - The arrangement should be made with the principal of Bana Ba Thari Special School.
  - During the research, applicable research ethics should be adhered to in particular the principle of voluntary participation, no photo shooting and names of participants should be mentioned
4. Upon the completion of research study, the researcher shall share the final product of the research with the school.
5. The school wishes you success in your investigation.

Yours sincerely

.....  
Principal

DEPARTMENT OF EDUCATION  
BANABATHARI SPECIAL SCHOOL  
FOR LEARNERS WITH INTELLECTUAL

20 JUL 2021

PO BOX 460 SOVENGA 0727

**APPENDIX H: PERMISSION LETTER SPECIAL SCHOOL B**

**T SOGA O ITIRELE SPECIAL SCHOOL**  
FOR THE SEVERELY INTELLECTUALLY DISABLED



LIMPOPO  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA  
DEPARTMENT OF  
EDUCATION

Box 2963  
Chueniespoort  
0745

1110 Mamaolo Village  
Ga-Mphahlele  
0745

EMIS NO: 923262058 Telfax: 015 634 0099

EMIS NO: 923262058

09/08/2021

Attention : Makgoga MT

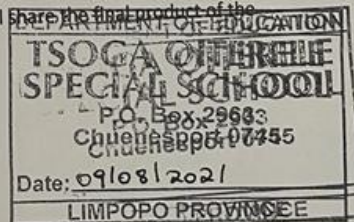
P.O. BOX 460

JANE FURSE

1985

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT T SOGA O ITIRELE SPECIAL SCHOOL

1. The above matter bears reference:
2. T SOGA O ITIRELE SPECIAL SCHOOL wishes to inform you that your request to conduct research has been approved by the stakeholders in the school. Topic of the research proposal: "experience of mother of children with severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province".
3. The following conditions should be considered when conducting your research.
  - The research should not have any financial implications to the school and interviewees.
  - The arrangement should be made with the principal of T SOGA O ITIRELE SPECIAL SCHOOL
  - During the research, applicable research ethics should be adhered to in particular the principal of voluntary participation, no photo shooting and names of participants should be mentioned
4. Upon the completion of research study, the researcher shall share the final product of the research with the school
5. The school wishes you success in your investigation



With thanks

*W. Phahlele M.A.*

Secretary (SGB)

*P.T. Mokoena*


Chairperson (SGB)

*W. Phahlele*

Principal

## APPENDIX I: PERMISSION LETTER SPECIAL SCHOOL C

**GRACE & HOPE LSEN SCHOOL**  
(FOR INTELLECTUALLY IMPAIRED)  
8296 ZONE 1 SESHEGO 0742  
Private Bag 4026 Seshego 0742  
E-Mail: [graceandhope@mweb.co.za](mailto:graceandhope@mweb.co.za)  
PAY POINT: 8229/412163, EMIS NO: 922223367  
TEL: 015 223 1086 / 015 223 4507 FAX: 015 223 7849 / 086 648 5223



**13 December 2021**

Enquiries Mafa M.N

082 065 8877 / 015 223 1086

**P.O BOX 460  
JANE FURSE  
1985**

Mr Makgoga M.T

### **REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT GRACE AND HOPE SPECIAL SCHOOL**

- The above matter bears reference
- The school kindly wishes to inform you that your request to conduct research has been approved. Topic of the research proposal: **'Experience of mother of children with severe intellectually disability regarding partner support in the Capricorn district, Limpopo Province'**.
- The following conditions should be considered when conducting your research.
  - The research should not have any financial implications to the school.
  - The arrangements should be made with the Principal.
  - During the research , applicable research ethics should be adhered to in particular with the principle of voluntary participation (the people involved should be respected).
- Upon the completion of research study, the researcher shall the final product of the research with the school.
- The school appreciates the contribution that you wish to make and wishes you success in your investigation.

Hope you find the above in order

Yours faithfully



## APPENDIX J: CODING CERTIFICATE

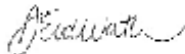
Dr Annatjie van der Wath (M Cur, PhD) [annavdw@mweb.co.za](mailto:annavdw@mweb.co.za)

### CODING CERTIFICATE Qualitative Data Analysis

This serves to confirm that Annatjie van der Wath has co-coded the following qualitative data: 12 interviews for the study:

**EXPERIENCES OF MOTHERS OF CHILDREN WITH SEVERE INTELLECTUAL  
DISABILITY REGARDING PARTNER SUPPORT IN THE CAPRICORN DISTRICT,  
LIMPOPO PROVINCE**

I declare that the candidate, Makgoga Malope Tshhegofatjo, and I have reached consensus on the major themes and categories as reflected in the findings during a consensus discussion.



Annatjie van der Wath (M Cur, Ph D) [annavdw@mweb.co.za](mailto:annavdw@mweb.co.za)

## APPENDIX K: EDITING LETTER



Makgoga Malope  
Tshegofatjo  
University of Limpopo

Sovenga

0727

---

420 Unit C Mankweng 0727

081 5666 755

rightmovemultimedia@gmail.com

Researcheditors882@gmail.com

karabokonyani@gmail.com

---

10 August 2022

TO WHOM IT MAY CONCERN

This editing certificate verifies that this dissertation was professionally edited for Makgoga Malope Tshegofatso.

Thus, it is meant to acknowledge that I, Mrs. K.L Malatji and Dr E.J Malatji professional Editors under a registered company Right Move Multimedia, have meticulously edited the manuscript from the University of Limpopo.  
Title: **“EXPERIENCES OF MOTHERS OF CHILDREN WITH SEVERE INTELLECTUAL DISABILITY**



**REGARDING PARTNER SUPPORT IN THE  
CAPRICORN DISTRICT, LIMPOPO PROVINCE " .**

Sincerely,

Mrs. K. L Malatji

A handwritten signature in black ink, appearing to read "K.L. Malatji", enclosed within a faint, light-colored oval border.

## APPENDIX L: TRANSCRIPT

### PARTICIPANT 5

**DATE OF THE INTERVIEW: 12/12/2021**

R: good day mom

P5: good day sir

R: how are you mom

P5: I am good and you sir

R: I am good too mom

R: I am Tshegofatjo Makgoga student at the University of Limpopo, doing a masters research in nursing. My topic is: experiences of mothers of children with severe intellectual disability regarding partner support in the Capricorn District, Limpopo Province. As I already explained that participation in this study is completely voluntary and that you may withdraw from the study at any time, without supplying any reasons and you may not be punished. As I already explained on the consent form that you already signed it can I stat with my interview questions

P5: yes you may start

R: how old is your child

P5: my child is 8 years old

R: do you know the condition that your child is suffering from

P5: he is suffering from autism

R: kindly describe your experiences regarding the support that you receive from your partner when caring for your severe intellectual disabled child

P5: my partner is showing us a support through the care that he has on our child. He is searching about the child's condition like as I do so that he can have full knowledge and understanding about our child's condition so that he can assist with the care of the child

R: is that all you have experienced from your partner mom

P5: yes is that all because he is very supportive to me and to our child

R: how did you and your partner feel for the first time when told that your child is having severe intellectual disability

P5: at first we didn't knew that the child is having this condition we knew it at later stage by our observation seeing that the child is having delayed milestone as compared to his age group. He develops later as compared to his aged group when they diagnosed him we just accepted that we are having this different child from others and we told ourselves that this is what God gave us.

R: even though the diagnoses come later but what was your feelings you and your partner

P5: it didn't came as a shock to us because we saw that our child has delayed milestones before diagnoses and after diagnoses we just accepted. It didn't come as a surprise because we saw him that he is having delayed milestones

R: how was the interaction between you and your partner after told that your child is having severe intellectual disability

P5: the treatment was the same as I already told you we accepted our child's condition and tried to find a way of raising a different child nothing changed

R: is your partner supportive in the care of your child

P5: yes he is supportive as I already told you that we are doing research about his condition because this condition is new to us. With the information from our search we think we can come up with solutions on how we can take care of this child. Sometimes I become emotional about this child and it became difficult hard for me to take care of this child then my partner is there for me to comfort me and support me emotionally. He is involved, he is a partner who is involved u see.

R: is your child getting social grant

P5: yes I just registered him this year

R: all this years was he not getting grant

P5: yes he was not getting grant I wasn't aware that my child qualify for the grant

R: ohk that's better because now you're getting child's grant

R: the time you were pregnant your partner was supporting you

P5: yes he was supporting me

R: even after giving birth was your partner still supporting you

P5: yes he did continue supporting me

R: when the child is going to the hospital for appointments your partner is going there with you and your child

P5: most of the time I was going to the hospital alone but I was informing him because he was working at another province far from us but I was updating him with everything they did and said about the child

R: if he didn't go with you at the hospital coming back is he is asking hospital feedback

P5: I did told you that I update him with everything concerning the hospital visit about the child

R: is the child staying at school or travelling to school everyday

P5: my child is staying at home travelling to school every day and he is transported by a family friend

R: how is paying the transport

P5: is paid by me we divided responsibilities we are having two children and I am the one responsible for their school fees and transport fees

R: is your partner proud of your child

P5: my partner is proud of our child he sometimes took him to parks and take long drive with him as my child likes car too much and again driving him to town involving him in same activities

R: is your partner able to remember the child's birthday

P5: he doesn't forget our child's birthday the first thing he do on his birthday he buy cake for him and due to his condition he cannot do many activities. My child doesn't not like noise so on his birthday we don't invite people we just celebrate as family and buy him his favorite gifts

R: are you buying Christmas clothes for the child

P5: ye Christmas clothes we do buy for him sir

R: when was it difficult times for you in taking care of your child

P5: the difficult times I had is when I was away from my child due to work, I am working far away from my child and I left him with other people and I wish I can be there for my child but not saying the once staying with him they are not taking care of him. That work take me away from my child and I spent less time with my child and I wish I can have more time to spend with him seeing him developing

R: is that all mom or you want to add

P5: no for now because I understand my child's condition that's why I don't have many difficulties in caring for my child

R: what are the challenges you experience from your partner

P5: I cannot really say is a challenge because you know us mother we have soft sport for children as compared to men. My partner spent little time with us so it is hard to pick the challenges from him because that little time he make sure that he spend it fruitfully

R: what do you think should be done to improve your partner support

P5: myself I do have support, emotional support and financial support he is there I don't want to lair. Those that are not supported they must involve their partners and try to make them to understand their child's condition. Us women we are the once who are attached to our children and we spend most of our time with them if you discover something involve your partner so that he can learn and develop interest in the care of the child

R: is that all you can say mom

P5: yes is that all I can say

R: do you have question to ask based on the interview we have just did before I close

P5: I don't have any question to ask or other things to share I said everything

R: can I close the interview

P5: yes you can close it brother

R: thank you mom for participating in my research

P5: thank you too my brother

R: thank you mom