Exploring the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust

By

Karabo Princess Zwane

16220154

A mini-dissertation

Submitted in partial fulfilment of the requirements for the degree

Master of Social Work (Healthcare)

MSW (Healthcare)

In the

Department of Social Work and Criminology

UNIVERSITY OF PRETORIA

FACULTY OF HUMANITIES

SUPERVISOR: Prof. N. Bila

30 April 2025

DECLARATION OF ORIGINALITY

The **Department of Social Work and Criminology** emphasises integrity and ethical conduct in preparing all written work submitted for academic evaluation.

While academic staff teach you about referencing techniques and how to avoid plagiarism, you, too, have a responsibility in this regard. If you are uncertain about what is required, you should speak to your lecturer before submitting any written work.

You are guilty of plagiarism if you copy something from another author's work (eg a book, an article or a website) without acknowledging the source and passing it off as your own. In effect, you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim), but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it. You are not allowed to use work previously produced by another student. You are also not allowed to let anybody copy your work to pass it off as their work.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The following declaration must accompany all written work submitted while you are a Department of Social Work and Criminology student. No written work will be accepted unless the declaration has been completed and attached.

Full name of student: Karabo Princess Zwane
Student number: u16220154
Topic of work: Exploring the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust

Declaration

1. I understand plagiarism and know the University's policy.
2. I declare that this mini-dissertation is my original work. Where other people's work has been used (either from a printed source, the Internet or any other source), this has been appropriately acknowledged and referenced by departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed, and will not allow, anyone to copy my work to pass it off as their work.

SIGNATURE

DATE
30 April 2025

ACKNOWLEDGMENTS

I would love to acknowledge the favour from my creator God, who has surrounded me like a shield throughout this degree journey.

Secondly, thanks to my husband and two kids, who have been pillars of strength, motivation, and support, even when financially it did not make sense, they supported me.

Thirdly, I want to express my utmost appreciation to my supervisor, Prof. Nontembeko Bila, for her support, guidance, counsel, and expertise during this mini-dissertation's initial stages and completion.

ABSTRACT

Exploring the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust.

RESEARCHER: Karabo Princess Zwane
SUPERVISOR: Prof. Nontembeko Bila
DEGREE: Master of Social Work (MSW) (Healthcare)
INSTITUTION: University of Pretoria

Many studies have explored intellectual disabilities (IDs) in children, but there is limited research on the mental health of parents caring for them. Parents caring for children with IDs are often faced with unique challenges and stressors that influence their mental health. While studies in mainly developed countries have examined this issue, there is still a lack of research focusing on the experiences of South African parents.

The purpose of the study was to explore the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities in Eersterust. It sought to identify the coping strategies parents use to manage stress, explore the sources of social support available to them and their impact on mental well-being, and explore and describe the role of resilience in promoting parental mental health. Additionally, the study aimed to provide recommendations for enhancing services and support systems for these parents.

A qualitative research approach was appropriate for this study as the researcher wanted to understand the lived experiences of parents caring for children with IDs. Five participants were purposively selected in Eersterust. Semi-structured interviews, comprising open-ended questions with an interview guide, were utilised to collect data, which were then analysed using reflexive thematic analysis.

The study identified seven key themes related to the experiences of parents caring for children with intellectual disabilities. The first theme focused on the emotional and psychological impact, highlighting struggles with denial and acceptance after diagnosis, fears about the child's future, and emotional exhaustion or burnout. Social challenges and exclusion emerged as another significant theme, with sub-themes including stigma and judgment, avoidance of social settings, and a general lack of awareness in the community. Financial strain was also a concern, particularly regarding the costs of diapers and specialised diets. Parenting challenges were explored, particularly difficulties in managing aggressive or disobedient behaviour, supporting social and emotional expressions, and navigating traditional and cultural beliefs. In terms of coping mechanisms, parents relied on faith and prayer, sought support from family, and used distractions and emotional control strategies. Despite these challenges, some positive aspects and personal growth were noted, such as celebrating their child's strengths and developing a greater awareness and understanding of intellectual disabilities. Lastly, the study presented several recommendations, emphasising the need for more substantial community support, increased awareness and positive attitudes toward intellectual disabilities, and improved access to resources and services.

The key findings can help improve support services by informing targeted interventions that address parents' emotional, social, and financial challenges. Raising awareness and reducing stigma can foster community acceptance and inclusivity, while parenting support programs can equip caregivers with strategies to manage behavioural challenges and navigate cultural beliefs. Improved access to resources, such as financial aid and specialised services, can ease the burden on families. Strengthening coping mechanisms through peer support and mental health initiatives can enhance resilience and well-being. Lastly, these findings highlight the need for further research on parental mental health in South Africa, ensuring long-term improvements in care and support systems.

Future research could expand on this study by exploring the experiences of parents caring for multiple children with intellectual disabilities and examining differences in stress levels, coping strategies, and support systems. Since only female participants were included in this study, future research should also explore the experiences of fathers, focusing on their mental health, caregiving roles, and coping mechanisms. Additionally, studying the perspectives of siblings of children with intellectual disabilities could provide a broader understanding of family dynamics and the overall psychosocial impact on parental well-being.

Key terms:

Child
Children with intellectual disabilities
Eersterust
Intellectual disability
Mental health
Parents
Psychosocial factors
Social work

Table of Contents

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1 COMPREHENSIVE INTRODUCTION

1.1. INTRODUCTION AND CONTEXUALISATION

Caring for children with intellectual disabilities presents unique challenges that can significantly influence the mental health of parents. A study in Malawi found that 41.2% of parents caring for children with intellectual disabilities reported psychological distress (Masulani-Mwale, Kauye, Gladstone, & Mathanga, 2018:146). Meanwhile, in Pakistan, these parents presented symptoms of depression, anxiety, or both (Azeem, Dogar, Shah, Cheema, Asmat, Akbar, Kousar, & Haider, 2013:290-291). In South Africa, similar challenges are evident. In KwaZulu-Natal, mothers with children aged 1 to 12 years with intellectual disabilities also reported clinically significant stress levels, in addition to increased restrictions in activities (32.8%), feelings of personal well-being (30.7%), and economic challenges (17.4%) (Mbatha & Mokwena, 2023; Paruk & Ramdhial, 2018).

It is evident through these statistics from a global to a local view that these parents face various psychological and social challenges as they care for their children with intellectual disabilities. The improvement of medical care on a global scale, as it continuously progresses, has shown an increase in the survival rate of children with intellectual disabilities (Masulani-Mwale et al., 2018:1-3; Salomon, Britt, Pollack & Trollor, 2018:2). Thus, the prevalence of intellectual disability might appear to be on the rise, especially in developing countries (Foskett, 2014:1-5; Masulani-Mwale et al., 2018:1-3). It has been estimated that 1 in 20 families globally includes at least one child with intellectual disability (Baker, Devine, Ng-Cordell, Raymond, IMAGINE-ID consortium & Hughes, 2021:315).

The parents/families face immense challenges, adding to the already overwhelming responsibilities associated with parenting. Parents caring for children with intellectual disabilities often face social isolation, economic hardship, and severe stress, leading to a higher risk of mental health problems (Hoyle, Laditka, & Laditka, 2021:3-4; Kütük, Tufan, Kılıçaslan, Güler, Çelik, Altıntaş, Gökçen, Karadağ, Yektaş, Mutluer, Kandemir, Büber, Topal, Acikbas, Giray, & Kütük. 2021:4087). Most studies on the psychosocial experiences of parents caring for children with intellectual disabilities have been conducted globally. However, there is limited research on similar studies or reviews within South Africa to showcase the impact. Consequently, a research study on the influence of psychosocial factors on the mental health of parents who assume caregiving responsibilities for children with intellectual disabilities in South Africa would be an excellent contribution to knowledge. The purpose of this research study was to explore and gain insight into the challenges faced by these parents and identify targeted interventions and support services to promote the well-being of the parents.

In this study, the following concepts should be consistently understood:

- **Child:** "A person under the age of 18 years" (The Children's Act 38 of 2005). In the context of this study, a child refers to the biological child of a participant, regardless of the child's age.

- **Children with intellectual disabilities:** "Children with intellectual disability have significant difficulties in both intellectual functioning (e.g. communication, learning, and problem-solving) and adaptive behaviour (e.g., everyday skills, routines, and hygiene)" (American Academy of Paediatrics (AAP), 2015). For this study, children with intellectual disabilities refer to persons who have been experiencing significant difficulties in intellectual and/or adaptive behaviour for a minimum of two years.

- **Eersterust:** "Eersterust is a formal South African township within the City of Tshwane located about 15km east of Pretoria city centre" (Wikipedia, 2025). Eersterust served as the location where the study took place.

- **Intellectual disabilities (IDs):** "Intellectual disabilities are neurodevelopmental disorders that begin in childhood and are characterised by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living" (Marais, Wegner & Mthembu, 2022:1). For this study, intellectual disabilities refer to a broad category (general) of intellectual impairments characterised by significant limitations in intellectual functioning and adaptive behaviours such as communication and self-care.

- **Mental Health:** “Mental health is a state of mental well-being that enables people to cope with the stresses of life, realise their abilities, learn well and work well, and contribute to their community” (World Health Organisation [WHO], 2022). Mental health in this context refers to the emotional, cognitive, and social aspects of a parent’s psychological state as they pertain to their ability to cope with the challenges associated with caring for a child with an intellectual disability.

- **Parents:** “‘Parent,’ concerning a child, includes the adoptive parent of a child, but excludes (a) the biological father of a child conceived through the rape of or incest with the child’s mother; (b) any person who is biologically related to a child by reason only of being a 20 gamete donor for purposes of artificial fertilisation; and (c) a parent whose parental responsibilities and rights in respect of a child have been terminated” (The Children’s Act 38 of 2005). Therefore, in this study, parents will refer to the biological mother or father or anybody assuming the role of caring for children with intellectual disability.

- **Psychosocial factors:** “Psychosocial factors are characteristics or facets that influence an individual psychologically and/or socially. Such factors can describe individuals in relation to their social environment and how these affect physical and mental health. Psychosocial factors include protective psychosocial resources and psychological risk factors” (Thomas, Nilsson, Festin, Henriksson, Lowen, Lof & Kristenson, 2020:2). These factors refer to the broad range of psychological, emotional, and social dimensions that shape the experiences of parents raising children with intellectual disabilities.

- **Social work:** “Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work” (South African Council for Social Service Professions, 2025).

1.2. THEORETICAL FRAMEWORK

This study utilised the ecological systems perspective developed by Urie Bronfenbrenner, who wanted to understand human development (Eriksson, Ghazinour & Hammarström, 2018:416). Since the inception of the ecological systems theory in the late 1970s, it has gone through significant changes (Eriksson et al., 2018:414), and in social work practice, it has given equal weight to the autonomy of people and the social environment (Cody & Lehmann, 2008:90). Meaning, that there is an interrelatedness between people and their environment (Shokane, Makhubela & Blitz, 2018:4).

For this study, the determinants of parents' mental health were understood using ecological systems thinking as a conceptual tool to guide mental health interventions. WHO (2022) encourages a need to assess several multi-layered factors to promote mental health and prevent mental illness. The advantage of utilising the ecosystem perspective is its multilevel approach to contextual psychosocial factors influencing parents and their children (with IDs); it capacitates social workers to view parents' experiences at various levels (Mbedzi, 2019:95-99). However, this perspective gives little attention to individual differences due to its broad scope; thus, possible recommendations might only apply to participants of this study (Kilanowski, 2017:296). Therefore, Bronfenbrenner described distinctive levels of the ecosystem perspective, namely, microsystem, mesosystem, exosystem, macrosystem, and chronosystem, outlined in the study context below.

Microsystem

This entails the "closest" connections between an individual and their immediate environment (Eriksson et al., 2018:419). For this study, it meant relations between the parent and the family members, especially his/her child with ID, and other social interactions such as the child's school. Evans (2023) discussed these relationships as bi-directional, denoting that the parent can influence their child, and the child can also change their parents' actions and beliefs. In support of what Evans (2023) stated, Patton, Ware, McPherson, Emerson & Lennox (2018:3) concur that as a result of stress, a parent's inconsistent parenting style could add to the behavioural difficulties in children with IDs.

Mesosystem

Refers to the interconnectedness and interactions among various microsystems in an individual’s life (Evans, 2023). These interactions are beyond the individual's settings, two or more immediate circles (Neal & Neal, 2013:725-726). For example, the interactions between the child (with ID) and his/her educators at school. Thus, the significant influence would be that if the child (with ID) is doing well and coping at school, having access to appropriate educational resources could lessen the burden of stress on the parent. Likewise, negative or imbalances in the mesosystem could lead to challenges that result in parental distress (McConnell & Savage, 2015:100).

Exosystem

This level incorporates social structures in which the individual does not participate directly, yet is affected (Shokane et al., 2018:312). This denotes that the individual is affected and influenced by interactions within this system. For instance, parents who quit their jobs because they cannot juggle work and family demands are more likely to expose their children to hostile socioeconomic conditions (McConnell & Savage, 2015:101); as a result, lack of access to childcare resources might increase parental distress.

Macrosystem

In this component, cultural elements influence the mental health of parents. A study was conducted in Cape Town to understand the role of spiritual healers regarding ID. The findings were encouraging as spiritual healers were willing to learn about ID and concerned about the stigma and discrimination faced by families affected by ID (Mkabile & Swartz, 2021). Therefore, cultural or religious beliefs that provide support rather than “blame” parents for their children’s IDs can lead to positive outcomes (American Psychiatric Association (APA), 2022:178-182; Vorster, 2019:599). Whereas, when parents are blamed for their child’s ID following cultural beliefs, stigma and/or discrimination increase, impacting both the parent and child (Morrison, 2023:25).

Chronosystem

This is the fifth level of the ecological systems theory. From a Biblical view, the word Chronos is a Greek word that means *time* (Pinilis, 2011). Therefore, this level explains the environmental changes that happen over a lifetime, influencing development, either externally or internally (Evans, 2023). In the context of the study, Chauke, Poggenpoel, Myburgh and Ntshingila, (2021:2) believe that parents of adolescents with IDs, compared to parents with younger children with IDs, have extra responsibilities and roles in taking care of them. Thus, this level considers the different timelines that might bring different experiences in an individual's life (Lau & Ng, 2014:425).

Consequently, the adoption of the ecosystem perspective was appropriate for exploring psychosocial factors affecting the mental health of parents with children with IDs, as it permitted the consideration of multiple interconnected and interdependent factors directly or indirectly related to the individual (Kamenopoulou, 2016:523). Understanding these systems within the five levels is essential for developing comprehensive interventions to support the mental health of parents with children with IDs. It is important to note that these levels often overlap and influence one another and thus do not operate in isolation (Bronfenbrenner, 1986; Mbedzi, 2019:87-89). The ecosystem perspective was well-linked during the study as it helped the researcher gain an understanding of how the biological, psychological, and social components of participants interacted with one another.

1.3. PROBLEM STATEMENT AND RATIONALE

Parents of children with intellectual disabilities often face unique challenges that can significantly impact their mental health. The psychosocial factors surrounding the caregiving experience may contribute to elevated levels of stress, anxiety, and depression among these parents (McConnell & Savage, 2015:100). Understanding and addressing these factors are crucial for the well-being of parents caring for children with ID. Despite the growing awareness of the impact of ID on families, there is a gap in research focusing specifically on the psychosocial aspects affecting the mental health of parents in this context, more specifically within the South African context, as there is a lack of reliable statistics published (Chauke et al., 2021:2; Masulani-Mwale et al., 2018; Peer & Hillman, 2014; Foskett, 2014).

While there is existing research in developed countries on the challenges faced by parents of children with ID, there is a noticeable gap in studies that comprehensively examine the psychosocial factors influencing the mental health of these parents. Only a few studies were conducted within the African context to understand the mental health of children with IDs (Masulani-Mwale et al., 2018; Foskett, 2014), with little information on the psychosocial factors affecting the mental health of the parents caring for the children with IDs. Therefore, this research aimed to fill this gap and provide a more nuanced understanding of the complexities involved. When the psychosocial factors contributing to the mental health of parents are investigated, the findings can be essential for developing targeted interventions. Moreover, findings from this research can inform the development of policies and support systems that cater to the psychosocial needs of parents with children with IDs.

McConnell and Savage (2015:100) argue that all families, with or without children with intellectual disabilities, need a daily routine to confront daily adaptive challenges. However, Azeem et al. (2013:291) believe that parents with children with intellectual disabilities are in greater need of help. Thus, the experiences of parents with children with IDs may vary based on cultural and societal factors; therefore, investigating psychosocial factors within diverse cultural contexts is crucial for developing interventions that are sensitive to the unique needs of different communities. Moreover, the identified psychosocial factors can enhance the parents' ability to adhere to treatment plans and engage in therapeutic interventions for their children. The mental health of parents can have a direct impact on the well-being of children with intellectual disabilities. Therefore, understanding the bidirectional influence of psychosocial factors between parents and children is critical for promoting positive family dynamics and ensuring optimal outcomes for both parties.

In this study, the researcher explored the influence of psychosocial factors on the mental health of parents caring for children with IDs in Eersterust. Based on the above, the overarching research question the study sought to answer was:

"What is the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust?"

1.4. GOAL AND OBJECTIVES

Goal

The goal of the study was to explore the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust.

To achieve this goal, the following objectives needed to be achieved:

Objectives

To explore the psychosocial factors that contribute to the mental health of parents caring for children with intellectual disabilities.

To identify the coping strategies that parents use to manage the stress associated with caring for their children.

To understand the sources of social support that parents receive and how it impacts their mental health.

1.5. OVERVIEW OF RESEARCH METHODS

This research study was exploratory as the researcher aimed to explore the influence of psychosocial factors on the mental health of parents caring for children with IDs (Babbie, 2021:90-92). Interpretivism was the research paradigm as the researcher wished to understand the participants' lived experiences while observing their subjective experiences and social context (Alharahsheh & Pius, 2020:41-43).

The most suitable research approach was qualitative for gathering rich data from the small sample of participants, which allowed the research to gain in-depth knowledge of the influence of psychosocial factors on the mental health of parents caring for children with IDs in Eersterust (Babbie, 2021:386-390). Thus, the qualitative research approach was employed in this study to explore the unique views and experiences of the participants.

The type of research was applied research, where the study's results could be used to inform existing and/or new social work strategies and interventions concerning the mental health of parents caring for children with IDs (Adler & Clark, 2015:360). The research design was an instrumental case study design, where the researcher used interviews to gain insight into the real-life experiences and contexts of the participants (Nieuwenhuis, 2020b:89).

The study population was parents caring for children with IDs in Eersterust. The researcher chose Eersterust because there is a training centre for the mentally and physically disabled within the community. Moreover, there is little research regarding the experiences of these parents within the South African context (Foskett, 2014:1-3). The researcher accessed the participant through Ms. Aurelia Hoods as a gatekeeper at the Eersterust Training Centre. Thus, purposive sampling as a form of non-probability sampling was used in the study to gather participants who met the inclusion criteria (Strydom, 2021:381-383); that is, parents of children (regardless of age) with IDs from Eersterust. The researcher gained information power after interviewing the fifth participant. Information power entails that a small sample can be used if a large amount of data relevant to a study is reached (Malterud, Siersma & Guassora, 2016:1753).

The interview method incorporated in the study was a semi-structured interview that allowed the researcher to remain flexible throughout the data collection process and collect rich data (Geyer, 2021:355; Nieuwenhuis, 2020 b:108). The interview was guided by an interview schedule with open-ended questions and structured ones, and the interview was conducted face-to-face. All interviews were voice-recorded using a cell phone and transcribed for data analysis using reflexive thematic analysis (RTA) (Braun & Clarke, 2022:1-3).

To ensure the study's trustworthiness, data quality was established through transferability, credibility, dependability, and confirmability (Nieuwenhuis, 2020a:143-144). Chapter 3 (Research Methodology) provides a more comprehensive account of these research methods, including the ethical considerations adhered to.

1.6. CHAPTER OUTLINE

The mini-dissertation is outlined as follows:

1.6.1 Chapter outline

The mini-dissertation consists of five chapters

Chapter 1: Comprehensive Introduction

This chapter presents a concise background of the study, explores the theoretical framework, outlines the problem statement and rationale, defines the research question, specifies the study's goal and objectives, and provides an overview of the research methodology.

Chapter 2: Literature Review

The literature review explores various aspects related to parents caring for children with intellectual disabilities (IDs), offering a comprehensive overview of relevant studies while highlighting existing gaps in recent research. It covers key topics such as the nature of ID, its impact on mental health, factors influencing parental caregiving, available intervention and support strategies, and the role of social workers in supporting parents of children with IDs.

Chapter 3: Research Methodology

Chapter 3 depicts a thorough discussion of the research methodology utilised in the study, including the research approach, type of research, research design, and research methods.

Chapter 4: Research Findings

Chapter 4 provides a presentation of the key findings of the study.

Chapter 5: Discussion and Recommendations

The concluding chapter analyses the study’s findings, assessing the extent to which the research goals and objectives were achieved while acknowledging its limitations. It then presents conclusions related to the research methodology, theoretical framework, and participants' biographical details. Finally, on the basis of the key findings, comprehensive conclusions are stipulated, and practical recommendations for future research are suggested.

Chapter two follows with the literature review.

CHAPTER 2 LITERATURE REVIEW

2.1. INTRODUCTION

Intellectual disability (ID) is a neurodevelopmental disorder characterised by limitations in intellectual functioning and adaptive behaviour, originating before the age of 18 (APA, 2022:178). It affects various aspects of daily life, including communication, social participation, and independent living (Schalock, Luckasson & Tasse, 2021). Parents of children with ID often face heightened emotional, financial, and social challenges, which can impact their mental well-being (Perron, 2017:198-200). Studies indicate that caregiving stress is linked to increased levels of anxiety, depression, and social isolation (Masulani-Mwale et al., 2018:1-3). Furthermore, stigma and inadequate support systems exacerbate these difficulties, highlighting the need for community-based interventions and mental health resources (McConnell, Savage & Breitkreuz, 2019).

This chapter first explores the overview of ID, including the signs and symptoms, the causes, and clarification, as well as ID in the context of South Africa. Secondly, the psychosocial factors affecting parents caring for children with ID – lastly, the coping strategies, including the role of social support in enhancing resilience and well-being.

2.2. OVERVIEW OF INTELLECTUAL DISABILITY

As defined above, intellectual disability (ID) is a disorder that limits an individual’s ability to learn and function in daily life at an expected level, such as communication and following up with routines (AAP, 2015; Marais et al., 2022). Therefore, an ID could cause a child to learn, speak, walk, and eat without help more slowly than other children of the same age. According to the Centres for Disease Control and Prevention (CDC, 2022), ID presents itself at any time before a child turns 18 years old, even before birth, which can vary widely in severity, ranging from mild to profound (AAP, 2015).

2.2.1 SIGNS AND SYMPTOMS OF ID

The signs and symptoms of ID can vary significantly depending on the severity of the condition [as outlined below under the clarification of ID] and its underlying cause. Individuals with ID often show developmental delays and may struggle to meet certain milestones (APA, 2022:180), but the specific symptoms they exhibit will differ from one person to another. Below are some key signs commonly observed in individuals with ID, as outlined by the CDC (2022):

2.2.1.1. Delays in Motor Development:

Individuals with ID may experience delays in achieving typical physical milestones such as sitting up, crawling, or walking. These delays occur because the cognitive and physical coordination necessary for these activities may take longer to develop than in their peers.

2.2.1.2. Delayed Speech and Communication Difficulties:

One of the most noticeable signs of ID is delayed speech development or challenges in communication. This can manifest in late onset of speaking, difficulty forming coherent sentences, or struggling to express needs and thoughts effectively. Language development may be slower, and some individuals may rely on non-verbal communication longer than others (APA, 2022:180).

2.2.1.3. Memory Retention Issues:

People with ID may encounter challenges with memory, including difficulty retaining and recalling information. This can impact their ability to learn new skills, remember important details, and follow instructions over time.

2.2.1.4. Struggles with Social Interaction:

Individuals with ID may have difficulty understanding social cues, such as body language, facial expressions, or the subtleties of communication (APA, 2022:180; Vorster, 2019:592). This often leads to challenges in forming and maintaining relationships and socially integrating. They may not fully grasp social norms or expectations in group settings.

2.2.1.5. Difficulty Foreseeing Consequences:

A hallmark of intellectual disability is the difficulty in understanding the potential outcomes of one's actions. This can lead to risky behaviour, as individuals with ID may not foresee the long-term impact of their decisions. They may also struggle with self-regulation, which can affect their ability to act in socially appropriate ways.

2.2.1.6. Problem-Solving Challenges:

People with ID often experience obstacles in problem-solving, especially in novel or complex situations. They may struggle to think critically or apply logical reasoning to resolve challenges, impacting their ability to perform everyday tasks that require independent thought.

These common signs and symptoms can be categorised into three key areas:

- Delayed Developmental Milestones: This includes delays in communication, motor skills, and cognitive development (APA, 2022:191-193). These delays are often one of the first signs parents or caregivers notice.
- Difficulties in Managing Emotions: Individuals with ID may find it challenging to regulate their emotions, which can result in frustration, anxiety, or emotional outbursts. They might have trouble understanding or expressing their feelings appropriately (APA, 2022:180-193).
- Behavioural Signs: In addition to cognitive and emotional difficulties, individuals with ID often display specific behavioural patterns. These may include repetitive behaviours, impulsivity, or difficulty following instructions and routines (Kendall & Owen, 2015:60-62). These behaviours are often an attempt to cope with frustration or a lack of understanding of social or cognitive expectations.

Overall, the symptoms of ID span across multiple domains, including motor development, communication, cognitive abilities, and emotional regulation. Identifying these signs early in life can help provide appropriate interventions, such as speech therapy, occupational therapy, and educational support. These are crucial in improving the quality of life and enabling individuals with ID to reach their full potential (Vorster, 2019).

2.2.2 CAUSES OF ID

The most common and possible causes of ID, as discussed by the National Institute of Child Health and Human Development (NICHD, 2021), are genetic mutations, additions, or deletions; chromosome abnormalities; substance exposure while the child is in the womb; problems during childbirth; preterm birth and traumatic brain injury. Various types of IDs are Down syndrome, Autism, Fragile X syndrome, Fetal alcohol spectrum disorders, Williams syndrome, Cerebral palsy, and Prader-Willi syndrome (Lee, Cascella, & Marwaha, 2023; Smiley, 2023). According to research, 9.4% of children in the United States have a developmental disability (Hoyle et al., 2021). Consequently, attention to the mental health status of parents, particularly pregnant women, seems to be imperative.

Initiatives such as the Perinatal Mental Health Project (PMHP, 2023) are established to address mental health conditions among pregnant and postnatal women in low-resource contexts, exemplifying concerted efforts to mitigate potential adverse developmental outcomes such as ID in offspring through proactive maternal mental health interventions. It is imperative to note that ID is a multifactorial condition where a combination of genetic and environmental factors can contribute to its development. So, not only does ID develop because of adverse prenatal exposures, but it also has a genetic basis (CDC, 2022).

This information on ID enriches the study by providing foundational knowledge and forming a basis for exploring the psychosocial factors that influence parental caregiving experiences; thus, it informs the development of effective interventions and support services for parents raising children with IDs.

2.2.3 CLARIFICATION OF ID

Intellectual Disability (ID) is characterised by significant limitations in intellectual functioning (IQ below 70) and adaptive behaviour, originating before the age of 18 (APA, 2022). The severity levels of ID are classified into four categories based on IQ scores and functional impairments:

2.2.3.1 Mild Intellectual Disability

Mild intellectual disability is the least severe category of intellectual disability, typically characterised by an IQ range of 50–70 (Vorster, 2019:592). Individuals with mild ID develop cognitive and adaptive skills more slowly than their peers but can attain basic literacy, numeracy, and self-care abilities with structured support (Vorster, 2019:594; APA, 2022:178-180). In childhood, they may experience challenges with problem-solving, attention, and abstract thinking, often requiring specialised educational interventions. Despite these difficulties, individuals with mild ID can benefit from inclusive education settings if given appropriate accommodations such as individualised learning plans, visual aids, and extended task time (APA, 2022:180-184; McKenzie, Milton, Smith & Ouellette-Kuntz, 2016:104-106). Research suggests that early intervention, including speech and occupational therapy, significantly improves outcomes for individuals with mild ID by enhancing their social and communication skills (Schalock et al., 2021:12-27).

Although individuals with mild ID can achieve a certain level of independence, they may face difficulties handling complex life decisions, financial management, and employment responsibilities (APA, 2022:180; Vorster, 2019:592-594). Most can work in structured environments, especially in roles involving repetitive tasks and routine procedures. Workplace adaptations, such as simplified instructions and on-the-job coaching, can help them sustain employment (Rosa, Schmidt & Delgado, 2023:35-37). Socially, individuals with mild ID often struggle with understanding social cues, forming relationships, and regulating emotions, leading to occasional misunderstandings or social withdrawal. Programs focusing on emotional intelligence and social interaction skills have effectively promoted confidence and community integration (Simplican & Leader, 2022:265-280).

2.2.3.2 Moderate Intellectual Disability

Moderate intellectual disability is associated with more noticeable developmental delays, particularly in language acquisition, problem-solving, and independent living skills, characterised by an IQ range of 35-49 (APA, 2022:181-183; Vorster, 2019:595). Individuals in this category often require structured learning environments and individualised educational programs to develop functional literacy, numeracy, and basic life skills (Vorster, 2019:594-596). While they may learn to read and write, their progress is slower, and they often rely on repetitive teaching strategies and hands-on learning methods. Assistive technologies, such as communication boards and adaptive software, have proven effective in enhancing learning experiences for individuals with moderate ID (Simplican & Leader, 2022:265-280). Studies highlight that workplace inclusion programs and job coaching significantly improve individuals' employability and retention rates with moderate IDs (Verdonschot, de Witte, Reichrath, Buntinx & Curfs, 2009:303-318).

2.2.3.3 Severe Intellectual Disability

Severe intellectual disability (IQ 20–34) is characterised by significant cognitive and adaptive limitations, often accompanied by physical impairments or other medical conditions such as epilepsy or sensory deficits (APA, 2022: 182; Vorster, 2019:596). Individuals with SID have limited verbal communication abilities and may rely on nonverbal cues, gestures, or assistive communication devices to express themselves (Vorster, 2019:596; APA, 2022:182). Their motor development is typically delayed, requiring assistance with basic activities such as feeding, dressing, and mobility (APA, 2022:182).

2.2.3.4 Profound Intellectual Disability

Profound ID is the most severe form of intellectual disability, characterised by significant limitations in both cognitive functioning and adaptive behaviour (APA, 2022:183; Vorster, 2019:597). Individuals with profound IDs typically have an IQ of 20–25 or below (Vorster, 2019:592-594). They require extensive support in all areas of functioning, including personal care, mobility, communication, and social interactions (Barlow, Durand, Du Plessis & Visser, 2017:613-615).

These individuals are often socially isolated due to the extent of their disability, and fostering social interaction is vital for improving their emotional well-being and creating opportunities for them to participate in community life. Communication difficulties are common among individuals with profound ID, so various strategies, including the use of sign language, picture exchange systems, and assistive technology, are employed to help them express their needs and interact with others (APA, 2022:183; Vorster, 2019:597). Family involvement is essential in providing continuous support, and caregivers often undergo specialised training to better understand and meet the complex needs of individuals with profound ID, also leading to burnout and/or exhaustion for both the individual and their parents (Barlow et al., 2017:613-615). Because individuals with profound ID often experience multiple health challenges, they may require lifelong medical care. Thus, Parents caring for children with profound intellectual disabilities usually face more intense psychosocial challenges that significantly impact their mental health compared to those caring for children with less severe forms of ID (Peer & Hillman, 2014:92-98; Vorster, 2019:597-599).

2.2.4 INTELLECTUAL DISABILITY IN THE SOUTH AFRICAN CONTEXT

Intellectual disability presents significant challenges in South Africa, mainly due to socio-economic disparities, inadequate healthcare access, and persistent stigma surrounding disabilities (Foskett, 2014:29-31; Vorster, 2019:588-590). Studies indicate that the prevalence of ID in South Africa is estimated to be around 3–5% of the population, with a higher incidence in impoverished and rural communities (Statistics South Africa, 2022; Foskett, 2014:29-31). Key contributing factors include malnutrition, limited access to prenatal and postnatal healthcare, birth complications, and exposure to environmental toxins such as alcohol and lead (Fieggen, Lambie & Donald, 2019:201-213).

Despite existing policies aimed at improving the lives of individuals with disabilities, implementation barriers continue to hinder progress. Many children with ID in developing countries such as S.A. experience delayed or lack of access to healthcare services, which can lead to delayed diagnoses, for example, preventing them from accessing early intervention services that are crucial for their cognitive and adaptive development (Capri, Abrahams, McKenzie, Mkabile, Saptouw, Hooper, Smith, Adnams, Swartz & Ockert, 2018:1).

2.2.4.1 Education and Intellectual Disability

South Africa has attempted to promote inclusive education through White Paper 6 on Special Needs Education (Department of Education, 2001), which advocates for integrating learners with disabilities into mainstream schools. While this policy provides a strong framework for inclusivity, many schools lack the necessary resources, trained educators, and adapted curricula to support learners with IDs effectively. Consequently, children with ID are often left behind academically, leading to high dropout rates and limited opportunities for further education. Special schools, which are designed to cater to learners with severe intellectual disabilities, exist in South Africa but are concentrated in urban areas, leaving many children in rural regions without access to specialised education (Foskett, 2014:29-31). The lack of transport, assistive technology, and individualised learning support further exacerbates educational inequalities.

2.2.4.2 Employment and Economic Inclusion

Securing employment remains a significant challenge for individuals with ID in South Africa. The Employment Equity Act (1998) and the White Paper on the Rights of Persons with Disabilities (RSA, Ministry for the Department of Social Development, 2016) mandate workplace inclusivity, yet practical implementation remains limited. Many individuals with ID struggle to find jobs due to stigma, lack of vocational training, and workplace discrimination (Trani, Moodley, Anand, Graham & Thu Maw, 2020). Supported employment programs, such as those offered by Down Syndrome South Africa (DSSA) and Epilepsy South Africa, have shown promise in providing job coaching, skills training, and sheltered employment opportunities, but these initiatives remain insufficient to meet the needs of the entire ID population. Government disability grants provide financial relief but are not enough to ensure economic independence for most individuals with IDs (Van der Westhuizen et al., 2022).

2.2.4.3 Stigma and Social Exclusion

Cultural beliefs and societal attitudes toward disability play a significant role in the exclusion of individuals with ID. In some communities, ID is still associated with supernatural causes, leading to stigma, social isolation, and discrimination (Mitter, Ali & Scior, 2019:3). Families may choose to hide children with disabilities due to fear of judgment, further limiting access to essential services. Public awareness campaigns, advocacy efforts, and disability rights organisations have made progress in changing perceptions, yet individuals with ID still face barriers to social inclusion, education, and employment (Mitter et al., 2019:3-5).

2.2.4.4 Healthcare and Support Services

Healthcare access for individuals with ID remains limited, particularly in rural and underserved areas (Foskett, 2014:29-31). Many individuals with moderate to severe intellectual disabilities require ongoing medical care, speech therapy, occupational therapy, and mental health support, but these services are often unavailable due to funding constraints and a shortage of trained professionals (Van der Westhuizen et al., 2022). Research suggests that integrating disability support services into primary healthcare settings could improve accessibility, but implementation has been slow due to resource limitations (Foskett, 2014:29-31). Additionally, caregivers of individuals with severe and profound intellectual disabilities face significant stress and emotional burdens (Barlow et al., 2017:613-615; Vorster, 2019:592-597), highlighting the need for more comprehensive caregiver training and respite care programs.

While South Africa has made legislative and policy strides in recognising and addressing the needs of individuals with intellectual disabilities, challenges remain in education, employment, healthcare, and social inclusion. Limited implementation of inclusive education policies, workplace discrimination, healthcare shortages, and cultural stigma all contribute to the continued marginalisation of individuals with ID. Addressing these challenges requires more vigorous policy enforcement, increased funding for disability services, community-based rehabilitation programs, and public awareness campaigns. Greater collaboration between the government, private sector, NGOs, and disability advocacy groups is essential in ensuring that individuals with ID have access to the education, healthcare, and employment opportunities they need to lead fulfilling lives.

2.3 PSYCHOSOCIAL FACTORS AFFECTING PARENTS CARING FOR CHILDREN WITH IDs

Caring for children with IDs presents unique challenges that can impact the mental health of parents. In South Africa, as in many other countries, various psychosocial factors affect the well-being of these parents. Islam, Rahman, and Akhtar (2022:211) state that parents caring for children with IDs commonly face increased psychological, social, physical, and financial challenges when compared to parents of children without such disabilities. The key factors affecting parents caring for children living with IDs are discussed.

2.3.1 PSYCHOLOGICAL FACTORS AFFECTING PARENTS

Parenting a child with an intellectual disability (ID) presents unique psychological challenges that can significantly impact parental well-being. Numerous studies (Azeem et al., 2013; Chauke et al., 2021; Masulani-Mwale et al., 2018; Patton et al., 2018) have established a strong link between caregiving responsibilities and increased psychological distress, including anxiety, depression, and chronic stress. The emotional and psychological burden stems from multiple factors, such as caregiving demands, stigma, financial strain, and uncertainty about the child’s future (McConnell & Savage, 2015).

2.3.1.1 Psychological Distress Among Parents

Studies conducted in various contexts have consistently reported higher levels of psychological distress among parents of children with intellectual disabilities compared to parents of neurotypical children. McConnell and Savage (2015) highlight that these parents experience heightened stress levels due to the increased caregiving demands and societal attitudes toward disability. Similarly, Masulani-Mwale et al. (2018) conducted a cross-sectional study in Malawi, where 41% of 170 parents caring for children with IDs reported experiencing psychological distress. This prevalence aligns with findings from Azeem et al. (2013) in Pakistan, where 35% of mothers exhibited anxiety symptoms, 40% met the criteria for depression, and 13% experienced both anxiety and depression based on DSM-5 evaluations.

Chauke et al. (2021) further contributed to this body of knowledge by conducting a qualitative study in Limpopo, South Africa, using semi-structured interviews with eight parents of adolescents with intellectual disabilities. One of the emerging themes was negative emotional responses such as anxiety, worry, and feelings of helplessness. These findings parallel those of the quantitative studies in Malawi and Pakistan, indicating that psychological distress among parents of children with intellectual disabilities is a global phenomenon that transcends economic and cultural contexts.

2.3.1.2 The Emotional Adjustment Process

The process of accepting a child’s diagnosis and adapting to the lifelong caregiving role can be emotionally taxing. Parents often undergo stages of grief, including denial, anger, bargaining, depression, and eventual acceptance (Kubler-Ross & Kessler, 2005). Studies suggest that parents frequently experience an initial period of emotional turmoil upon receiving the diagnosis, which can later evolve into chronic stress if adequate coping mechanisms and support systems are not in place (Patton et al., 2018).

Furthermore, research has identified that parents of children with IDs often experience a sense of social isolation and stigmatisation, which exacerbates their psychological distress. In many low- and middle-income countries (LMICs), negative societal perceptions about disabilities contribute to parental stress (Masulani-Mwale et al., 2018). Parents may struggle with feelings of shame, self-blame, or fear of discrimination, further heightening their anxiety and depressive symptoms (Chauke et al., 2021).

2.3.1.3 Implications for Further Research

Despite extensive research in high-income countries, there remains a gap in understanding the psychological experiences of parents in LMICs, where access to mental health services and disability support systems may be limited. As Chauke et al. (2021) argue, more qualitative, in-depth studies are necessary to explore the lived experiences of parents, especially in communities such as Eersterust. Inductive research approaches could provide richer insights into these parents' coping strategies, resilience factors, and psychosocial support needs.

The research aims to contribute to the growing body of literature by focusing on the psychological factors affecting parents in Eersterust. By gaining a deeper understanding of their experiences, the study seeks to inform interventions that promote mental health support and resources tailored to the unique challenges faced by parents caring for children with intellectual disabilities.

2.3.2 STIGMATISATION, SOCIAL ISOLATION, AND SOCIAL SUPPORT SYSTEMS AFFECTING PARENTS

Parents of children with IDs frequently encounter significant social challenges, including stigma and social isolation, which can severely impact their mental health, social engagement, and overall well-being. While much of the literature has focused on the stigma experienced by individuals with IDs, research suggests that stigma extends to their families, leading to psychological distress, social exclusion, and limited access to support networks (Mitter, Ali & Scior, 2019). Scior (2016) highlights how stigma affects both individuals with disabilities and their caregivers, creating barriers to inclusion and support. Despite the widespread prevalence of this issue, there is a lack of research on the specific impact of ID stigma on parents, highlighting the need for further exploration.

2.3.2.1 Stigma and Its Impact on Parents

Stigma can be understood as a process of labelling, stereotyping, and discrimination, where individuals with intellectual disabilities—and their caregivers—are often perceived as socially or cognitively impaired (Link & Phelan, 2001, cited in Scior, 2016). Mitter et al. (2019) classify stigma into four primary forms that affect families:

- *Public stigma*: The negative societal attitudes and prejudices toward families with a child who has an intellectual disability, leading to discrimination in education, employment, and social settings.
- *Self-stigma:* The internalisation of societal prejudices, where parents begin to feel ashamed or responsible for their child's condition, often resulting in guilt and self-blame.
- *Family stigma (or courtesy stigma):* Negative judgments directed at the family as a whole, leading to social distancing and exclusion from extended relatives, friends, and the community.
- *Affiliate stigma*: When caregivers internalise societal stigma, they develop low self-worth and emotional distress, which may cause them to withdraw from social interactions and isolate themselves.

2.3.2.2 Cultural beliefs and stigma

Cultural beliefs and practices deeply shape how parents perceive, experience, and navigate the challenges of raising a child with an intellectual disability (ID). In many societies, cultural norms, traditional beliefs, and community perceptions influence parental stress, coping mechanisms, and access to support systems. These cultural factors can either enhance resilience or intensify stigma and isolation, ultimately affecting the mental well-being of caregivers.

2.3.2.2.1 Community perceptions and social stigma

In some African cultures, disabilities are sometimes viewed as a curse, punishment for past sins, or a result of witchcraft (Masulani-Mwale et al., 2018:6; Hartley, Ojwang, Baguwemu, Ddamulira, and Chavuta, 2005:155). Such belief systems can cause guilt and self-blame among parents who may feel they are being punished for past actions (Gona, Mung'ala-Odera, Newton & Hartley, 2011:185). Another belief is that the disability is contagious, and thus, parents may isolate and avoid talking about their child's condition due to fear of exclusion and judgment (Mckenzie & McConkey, 2016:3).

2.3.2.2.2 Traditional gender roles and caregiving expectations

Cultural norms often dictate who should take on caregiving responsibilities, significantly influencing the stress level experienced by parents. In many societies, women are expected to be the primary caregivers (Masulani-Mwale et al., 2018). This expectation often leads to financial strain, emotional exhaustion, and social isolation for mothers as they balance caregiving responsibilities with limited support systems. In contrast, fathers are usually expected to focus on providing financial support rather than being actively involved in caregiving. This dynamic can increase the stress and burden on mothers, potentially leading to marital conflicts or strained family relationships (Gona et al., 2011). Furthermore, extended family members play a significant role in caregiving in some cultures. While this can offer valuable social support, it may also create tensions when family members impose traditional healing practices or blame parents for the child's condition rather than embracing medical interventions (Hartley et al., 2005). This complex web of caregiving expectations can exacerbate parental stress, complicating the experience of caring for a child with ID

2.3.2.2.3 Cultural strengths and resilience

While cultural beliefs can sometimes create barriers for parents caring for children with intellectual disabilities, they can also provide protective factors that enhance parental resilience. For many parents, religious faith serves as a powerful coping mechanism, offering emotional and psychological strength. They may view their child as a blessing rather than a burden, which helps them navigate the challenges of caregiving (Masulani-Mwale et al., 2018).

Additionally, in cultures where community support systems are emphasised, parents often receive valuable assistance from relatives, neighbours, and religious groups, which can significantly ease the caregiving burden. Moreover, traditional wisdom and adaptive strategies, such as indigenous healing practices and traditional parenting methods, can complement modern therapies, providing a more holistic approach to care. These cultural strengths not only support parents in their caregiving roles but also contribute to their ability to cope with and adapt to their challenges.

2.3.2.3 Social Isolation and Its Consequences

The experience of stigma often leads to social withdrawal, as parents may feel excluded, judged, or misunderstood by their communities. Social isolation is particularly concerning because it deprives caregivers of emotional support, which is crucial in managing the stress of raising a child with intellectual disabilities. A qualitative study by Currie and Szabo (2020) found that parents of children with neurodevelopmental disorders experienced significant exclusion from social systems, including family networks, religious institutions, and even healthcare services. Many parents reported feeling unwelcome in public spaces, struggling to access social opportunities, and facing a lack of understanding from others. Some even described themselves as "invisible" in their communities, leading to heightened emotional distress and loneliness (Currie & Szabo, 2020).

Understanding the interplay between stigma, cultural beliefs, and social isolation is crucial in addressing the challenges faced by caregivers of children with IDs. By fostering greater awareness, expanding support networks, and advocating for inclusive policies, communities can help reduce caregiver burden and promote well-being among parents. Addressing these social factors is essential in creating a more inclusive and supportive environment for families affected by intellectual disabilities.

2.3.3 FINANCIAL STRAIN AND ITS IMPACT ON PARENTS

Caring for a child with an intellectual disability (ID) presents significant financial challenges, which can lead to economic instability, increased stress, and psychological distress among caregivers. The World Health Organisation (WHO, 2023) acknowledges the growing burden of mental health problems and highlights the link between poverty and mental health vulnerability. Knifton and Inglis (2020:193) reinforce this by stating that individuals from low socioeconomic backgrounds are disproportionately affected by mental health issues due to financial stressors, inadequate access to healthcare, and limited social support systems.

2.3.3.1 The Relationship Between Socioeconomic Disadvantage and Psychological Distress

Masulani-Mwale et al. (2018:5) and McConnell and Savage (2015:101) establish a strong association between low socioeconomic status and psychological distress among parents caring for children with intellectual disabilities. While many studies emphasise the emotional and psychological toll of caregiving, McConnell and Savage (2015:101) argue that the higher-than-average levels of psychological distress observed in these parents may stem not only from the caregiving demands but from broader socioeconomic disadvantages. These financial struggles include increased healthcare costs, job disruptions, and limited access to social welfare benefits, which all contribute to chronic stress and diminished mental well-being.

2.3.3.2 The Financial Burden of Raising a Child with Intellectual Disabilities

Parents of children with IDs often encounter higher financial demands than those of typically developing children. Genereaux, Van Karnebeek, and Birch (2015:646) outline several key financial stressors, including:

- Medical Expenses: Many children with intellectual disabilities require regular medical check-ups, specialised treatments, medications, and therapeutic interventions (such as physiotherapy, occupational therapy, and speech therapy), which can be costly, especially for families without adequate health insurance.

- Assistive Devices and Specialised Equipment: Depending on the child's condition, families may need to purchase mobility aids, communication devices, or adaptive learning materials, adding to the financial burden.
- Educational Costs: While some children with intellectual disabilities attend specialised schools or inclusive education programs, the additional costs associated with special education resources, private tutoring, or therapy-based learning interventions can be substantial (Genereaux et al., 2015:646).
- Transportation Costs: Accessing healthcare and specialised education often requires frequent travel, particularly in low-resource settings where disability services are centralised in urban areas, making transportation costs a recurring expense.

2.3.3.3 Employment Challenges and Loss of Income

One of the most significant financial challenges faced by parents of children with intellectual disabilities is the difficulty of maintaining stable employment. Research shows that:

- Increased Care Responsibilities: Compared to parents of typically developing children, caregivers of children with intellectual disabilities spend more time attending to their child's daily needs, medical appointments, and therapy sessions (Genereaux et al., 2015). This often results in reduced working hours or even job loss.
- Limited Workplace Flexibility: Many workplaces lack flexible work arrangements that accommodate parents with caregiving responsibilities, forcing some to quit their jobs or accept lower-paying, part-time positions.
- Unemployment and Gendered Financial Strain: In many households, mothers are more likely to leave formal employment to become full-time caregivers (Masulani-Mwale et al., 2018), leading to increased financial dependence on a single income source. This is particularly concerning in low-income settings where financial security is already fragile.

2.3.3.4 The South African Context: Limited Economic Opportunities and Financial Strain

South Africa's high unemployment rate and economic inequality exacerbate financial strain for families of children with intellectual disabilities. In a country where many families already struggle with economic hardships, the additional burden of caregiving can widen financial disparities and limit access to essential services. Some key challenges in the South African context include:

- Inadequate Social Grants: While South Africa offers disability grants and caregiver assistance, these are often insufficient to cover the full cost of caregiving (Department of Social Development, 2022). Many parents report that the grant amount does not keep up with inflation or the rising costs of specialised care.
- Limited Public Support Services: Public healthcare and special education services are often overburdened and under-resourced, leaving families to seek private alternatives, which may be unaffordable.
- Informal Employment and Financial Insecurity: A significant proportion of South African caregivers work in the informal sector, where job security, stable income, and employee benefits are lacking, further increasing financial instability.

2.3.4 PHYSICAL CHALLENGES IN CARING FOR CHILDREN WITH IDs

Caring for children with intellectual disabilities (ID) often involves significant physical challenges that can impact the well-being of parents and caregivers. These challenges are multifaceted, involving both the physical demands of caregiving and the long-term physical toll of managing a child’s condition. Parents of children with intellectual disabilities often face increased physical demands, as children with ID may require assistance with daily activities such as bathing, feeding, mobility, and hygiene (Genereaux et al., 2015). These tasks require significant physical energy and time, particularly when the child’s disability is severe or associated with other health complications. In many cases, parents must provide 24-hour care, leading to physical exhaustion and a lack of time for personal rest or self-care.

2.3.4.1 Impact on Parents' Health

The physical strain associated with caregiving often manifests in chronic fatigue and stress-related health conditions. Studies have shown that caregivers experience higher rates of back pain, headaches, and sleep disturbances, particularly if the child's behaviours are challenging or if the caregiving role is not shared (McConnell & Savage, 2015). Additionally, the physical burden can exacerbate existing health problems, leading to an overall decline in the caregiver's health, which in turn may affect the quality of care provided to the child.

2.4 COPING STRATEGIES FOR PARENTS

Coping strategies play a crucial role in mitigating parental burnout and enhancing overall well-being (Peer & Hillman, 2012:47). Coping is defined as a mindset and an action-oriented practice that individuals frequently use to manage demands that exceed their available resources (Peer & Hillman, 2014:47). Effective coping mechanisms allow parents to navigate the emotional, physical, and social challenges associated with raising children with intellectual disabilities. Peer and Hillman (2012) identified two primary coping strategies:

- **Problem-Focused Coping Strategy**: This approach involves taking active steps to address and resolve the problem causing stress. It includes seeking information, accessing support services, implementing structured routines, and advocating for the child's needs. Parents using this strategy might focus on learning about their child's condition, accessing special education programs, or working with healthcare professionals to develop intervention plans. The study found that this strategy was preferred by most parents, as it significantly reduced their stress levels while caring for their children with intellectual disabilities (Peer & Hillman, 2014).

- **Emotion-Focused Coping Strategy**: This approach targets managing the emotions associated with stress rather than directly solving the problem itself. Techniques such as mindfulness, self-care, emotional expression, and seeking emotional support from friends, family, or professionals fall under this category. Parents who struggle with feelings of frustration, guilt, or anxiety may find comfort in therapeutic interventions, counselling, or peer support groups. This strategy helps parents healthily process their emotions, preventing long-term mental health challenges.

2.4.1 Access to Healthcare as a Coping Mechanism

Beyond individual coping strategies, structural support such as access to high-quality healthcare services is essential for parental mental well-being (Werlen, Gjukaj, Mohler-Kuo, & Puhan, 2019:1-2). Parents who can quickly and easily obtain effective treatments and therapies for their child's medical or developmental challenges often report lower levels of stress and improved mental health (McConnell & Savage, 2015:100-104). Access to healthcare services, including regular medical check-ups, therapy sessions, and early intervention programs, ensures that children with intellectual disabilities receive appropriate care, reducing parental anxiety and enhancing their capacity to cope with caregiving demands (Norlin & Broberg, 2013:552-554; APA, 2022:178-182; Vorster, 2019:592-597).

2.4.2 The Role of Social Workers in Supporting Parental Coping

Social workers play a crucial role in assisting parents of children with intellectual disabilities by providing tailored interventions and support. Kavaliauckiene and Rimkuviene (2017:155) highlight a variety of social work skills essential for working with individuals with disabilities, including communication, observation, listening, and assessment skills. These skills enable social workers to:

- **Conduct Family Assessments**: Social workers assess the unique needs of each family and develop individualised care plans that address specific challenges and goals (Bigby & Frawley, 2018:96). This holistic approach ensures that parents receive targeted support that aligns with their personal and situational circumstances.
- **Provide Information and Education**: Many parents struggle with understanding the complexities of their child's ID. Social workers help bridge this gap by offering relevant information, resources, and training on caregiving

strategies, behavioural management, and available support services (McConnell & Savage, 2015:100-102; APA, 2022:180-182)

- **Advocate for Inclusion**: Ensuring that children with intellectual disabilities receive equal access to education, healthcare, and community services is a key role of social workers. By advocating for inclusive policies and programs, social workers help create supportive environments that ease the burden on parents (Peer & Hillman, 2014:92-96; Vorster, 2019:594-597).
- **Facilitate Access to Support Services**: Social workers connect parents to essential support systems, including financial aid programs (Foskett, 2014:2), respite care, specialised educational services, and counselling (Bigby & Frawley, 2018:96-100; APA, 2022:182). This access reduces the financial and emotional strain on families and enhances their ability to cope with daily caregiving responsibilities.

2.4.3 Peer Support and Community Engagement

Another critical coping strategy is fostering peer support and community engagement. Parents of children with intellectual disabilities often benefit from connecting with others facing similar challenges. Peer support groups provide a platform for sharing experiences, emotional support, and practical advice (Werlen et al., 2019). Community-based organizations and online forums offer opportunities for parents to exchange coping strategies, reducing feelings of isolation and fostering resilience.

2.5 SOUTH AFRICAN LEGISLATIONS AND POLICIES CONCERNING ID

The Constitution of South Africa (Act 108 of 1996) serves as the supreme law of the country that protects the rights of persons with disabilities. For example, Section 9 prohibits discrimination based on disability. The White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2015) promotes inclusive education and skills development for children with IDs, ensures access to healthcare, strengthens social support for families with IDs, and facilitates the economic empowerment of persons with disabilities. Moreover, the Mental Health Care Act (Act 17 of 2002) protects the rights of individuals with ID, ensuring they receive appropriate care, treatment, and rehabilitation.

2.6. SUMMARY

This chapter provided a literature review on the overview of ID, including the signs and symptoms of ID, the causes, and the clarification of ID within the context of South Africa. More emphasis was placed on the psychosocial factors affecting the mental health of parents caring for children with IDs. The literature review detailed psychological distress, stigma, social isolation, financial strain, and physical challenges. Studies reveal that these parents experience higher levels of anxiety, depression, and chronic stress due to caregiving demands, societal stigma, and economic hardships. Cultural beliefs also play a significant role, with some communities viewing disabilities as a curse or punishment, leading to further isolation.

Parent coping strategies are discussed, including problem-focused and emotion-focused approaches, access to healthcare, social worker interventions, peer support, and community engagement. Social workers play a crucial role in providing education, advocacy, and connecting families to resources. The discussion concludes with an overview of South African policies related to ID, such as the Constitution, the White Paper on the Rights of Persons with Disabilities, and the Mental Health Care Act, which aim to protect individuals with disabilities and ensure access to education, healthcare, and social support.

The following chapter depicts a thorough discussion of the research methodology utilised in the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter discusses the research methodology used during the study. It describes the research goal and objectives, followed by the research approach, type, design, and methods. The research methods section provides a closer look at the study population, sampling method, data collection, data analysis, data quality, and the pilot study implemented in the study. Finally, the ethical considerations and their methods of use are described.

3.2 GOAL AND OBJECTIVES

Goal

The goal of the study was to explore the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust.

To achieve this goal, the following objectives needed to be achieved:

Objectives

- To explore the psychosocial factors that contribute to the mental health of parents caring for children with intellectual disabilities.
- To identify the coping strategies that parents use to manage the stress associated with caring for their children.
- To understand the sources of social support that parents receive and how it impacts their mental health.

3.3 RESEARCH APPROACH

This study employed an exploratory research approach (Babbie, 2017) to understand the subjective experiences of parents responsible for caring for children with IDs. The ontological foundation that guided this research is rooted in the constructivist paradigm, an offshoot of the interpretivism paradigm as articulated by Adom, Ankrah, and Yeboah (2016:1). The interpretivism paradigm posits that individuals shape their comprehension and knowledge of the world through their lived experiences (Adom et al., 2016:2); thus, assumes that the very knowledge can be acquired through understanding the interpretations and experiences of an individual as shaped by social and cultural contexts (Ryan, 2018:14). Consequently, this research delved into the subjective realities of parents caring for children with IDs, emphasising the construction of meaning in their lives within the constructivist framework. The interpretivism paradigm assisted the researcher in gaining an understanding of the participants' experiences and interactions and the effect that these experiences have on their mental health as they care for children living with IDs. The researcher acted as both an observer and interpreter. This promoted reflexivity and facilitated knowledge transfer by interpreting the meaning behind participants' social experiences and interactions (Ryan, 2018:14). In summary, the interpretivism paradigm played a crucial role in this study by enabling the researcher to explore and interpret the subjective realities of parents caring for children with IDs. Through its emphasis on lived experiences and socially constructed meanings, this paradigm allowed for a deeper understanding of how these parents navigate their daily challenges and how these experiences impact their mental health. Ultimately enriching the study's insights into the influence of psychosocial factors on these parents' mental health through the utilisation of semi-structured interviews (Geyer, 2021:358).

The selected research paradigm aligned with the qualitative approach, which suited the exploratory nature of this study. The researcher aimed to gain an in-depth understanding of the participants' lived experiences within their unique settings using semi-structured interviews to collect data, which was analysed through reflexive thematic analysis (RTA) (Babbie, 2021:387-390). Qualitative research, characterised by its focus on in-depth exploration and understanding of the central phenomenon under investigation (Tenny, Brannan & Brannan, 2022), was deemed appropriate for exploring the influence of psychosocial factors on the mental health of parents of children with IDs within their natural contextual setting. The qualitative approach facilitated the collection of rich and intricate data (Babbie, 2017:30-32), allowing the researcher to identify recurring themes and patterns inherent in the participants' subjective experiences. Advantageously, the qualitative approach allowed the researcher to use a smaller sample size (Leedy & Ormrod, 2015:273) and gather rich data through the concept of information power (Malterud et al., 2016:1753). These methods linked well with the ecological systems perspective that outlines the microsystem, mesosystem, macrosystem, exosystem, and chronosystem, which are multiple levels to understand the interplay of factors that influence human behaviour (Bronfenbrenner, 1992:191-195). This theoretical framework enabled the researcher to explore holistically and understand the parents' experiences caring for children with IDs (Bronfenbrenner, 1992:191-195; Babbie, 2021:386-390).

3.4 TYPE OF RESEARCH

The appropriate type of research for the study that was utilised was applied research. Applied research applied to the study, taking into consideration that empirical research around the influence of psychosocial factors on the mental health of parents caring for children with IDs was limited at the time of the study and considering the problem statement and rationale of the study. Compared to basic research, which aims mainly to expand theories, applied research is useful in solving immediate or future problems and also suggests action or increases effectiveness in some practice areas (Adler & Clark, 2015:360; Rubin & Babbie, 2017:145). In this context, the collected data can contribute valuable insights to the field of social work, informing evidence-based decisions and enhancing the delivery of services, interventions, and programs targeted at addressing the psychosocial factors influencing the mental health of parents caring for children living with IDs. For the study, a subtype was not applicable.

3.5 RESEARCH DESIGN

A case study design was followed as it enabled the researcher to maintain the exploratory purpose, to fully understand the influence of psychosocial factors on the mental health of parents with children with IDs. A case study is a qualitative research design that studies a case within a real-life setting as the researcher becomes immersed in the participants' language, lives, and activities in the context of the case (Nieuwenhuis, 2020b:89). The study aimed at exploring a single case, that is, the influence of psychosocial factors on the mental health of parents caring for children with IDs, thus, the single case study was the most appropriate (Nieuwenhuis, 2020b:90). Therefore, it was an advantage for the researcher to have a direct and close relationship with the parents, where the parents were able to share their side of the story. In addition, the case study allowed the researcher to explore the lived experiences of a small sample using the interpretivism paradigm (Nieuwenhuis, 2020b:90), However, the use of the case study design was time-consuming, and empirical findings might not be generalisable to parents outside of the study (Schurink, Schurink & Fouché, 2021b:302-303). The instrumental case study helped provide insight into the psychosocial factors affecting the mental health of parents caring for children with IDs. Ultimately, the case study design allowed the researcher to enter the field with knowledge of the relevant literature, i.e. about ID, before conducting empirical. This can help refine existing theories, and knowledge could be used for future research and improve social work service delivery and related fields (Nieuwenhuis, 2020:90; Rubin & Babbie, 2017:145; Schurink et al., 2021b:304).

3.6 RESEARCH METHODS

This section covers the following topics: study population and sampling, data collection, data analysis, data quality, and pilot study as research methods that were utilised in the study.

3.6.1. Study population and sampling

A population is “the entire set of individuals or other entities to which study findings are to be generalised” (Engel & Schutt, 2013:112). The study population comprised parents caring for children with IDs in Eersterust. Given the qualitative nature of this research, the study sought to understand the lived experiences of parents caring for children with IDs, rather than produce generalisable findings applicable to a broader population. Qualitative research focuses on well-defined populations that provide in-depth, contextual insights relevant to the study’s objectives (Babbie, 2021:386-390; Leedy & Ormrod, 2015:270-272). The sampling approach utilised for this study was the non-probability sampling approach. Thus, the non-probability sampling approach was utilised as it does not make a random selection of the sample of interest (Strydom, 2021:381-383), i.e. parents caring for children with IDs. This approach was appropriate as it allowed the researcher to select participants based on the specific characteristics that align with the research focus. Therefore, the sampling method selected for this study was the purposive sampling method, which entails that the sample was purposefully chosen as it illustrates features the researcher is interested in (Maree & Pietersen, 2020:220). In this case, parents of children with IDs in Eersterust were selected as they could provide firsthand insights into the influence of psychosocial factors on their mental health. Participants were selected based on their role as parents of children with intellectual disabilities. Some were also employed at the centre where their children receive care, often in caregiving or support roles. However, their inclusion in the study was based solely on their parental experiences, and data collection focused on their psychosocial experiences in that capacity.

The researcher chose Eersterust as the research site, as there was a centre/school and training facility for people and children with disabilities at the time of the study, i.e., Eersterust Care and Training Centre. This location provided an accessible and relevant setting where potential participants could be identified. A gatekeeper, the director of the Eersterust Care and Training Centre, facilitated access to potential participants by identifying and notifying them about the study. The participants were then given a study information sheet outlining the research's purpose, nature, and goals before being invited to participate. The study's sample size was determined using information power rather than data saturation. Information power suggests that fewer participants are needed when researchers have access to rich and relevant data for their specific study (Malterud, et al., 2016:1753). Factors such as the study's focused objective (examining parents in Eersterust), the high specificity of the sample (parents of children with intellectual disabilities), the theoretical framework (ecosystem perspective), the qualitative data collection method (semi-structured interviews), and the data analysis approach (reflexive thematic analysis) all contributed to the feasibility of achieving high information power with a relatively small sample size (Malterud et al., 2016:1753-1755). The researcher interviewed five participants, and the strong quality of the gathered discussions indicated that recruiting more participants would be unnecessary and could diminish potential data (Malterud et al., 2021:67-70). Given the qualitative nature of the study, emphasis was placed on depth rather than breadth, qualitative research prioritises rich, detailed narratives that provide meaningful insights into participants' lived experiences (Babbie, 2021:386). This approach ensured that the study captured the complexity of parenting experiences without requiring a large sample size. Furthermore, the interpretivist paradigm supports the idea that meaning is constructed through social interactions and individual perspectives, making an in-depth engagement with fewer participants more valuable than broad generalisation (Alharahsheh & Pius, 2020:41-43; Junjie & Yingxin, 2022:10-12).

Ethical considerations were also integral to the participant selection process. Permission was requested from the Eersterust Care and Training Centre director, Ms.

Aurelia Hoods, to identify and notify any potential study participants and then share with them the study information sheet outlining the purpose, nature, and goal. The interested participants were then given the informed consent letters to read through, share any questions they had with the researcher, and sign before participating in the study. The researcher ensured that all participants fully understood their rights, including their ability to withdraw at any stage without consequences. Once consent was obtained, interviews were conducted at the Eersterust Training Centre in a safe and private environment to protect participant confidentiality and encourage open, honest discussions. Through Ms. Aurelia Hoods as the gatekeeper, information about the study was sent to participants who met the following inclusion criteria:

- Parents with children with an intellectual disability, with no age range for the child.
- The minimum period of two years during which the child has been living with an intellectual disability.
- Parents residing in Eersterust, Tshwane, Gauteng province.
- Parents who can read, write, and converse in English.

3.6.2. Data collection

The data collection method that was used during the study was semi-structured interviews. This method allowed the researcher to collect rich data, gaining access to a deeper understanding of the contextual lives of the parents caring for children with ID (Geyer, 2021:355; Nieuwenhuis, 2020:108). Unlike structured interviews, which follow a rigid question format, semi-structured interviews provide flexibility, enabling the researcher to explore, probe, and clarify responses as necessary (Nieuwenhuis, 2020:108). The semi-structured interviews were voice recorded and consisted of open-ended questions. The disadvantage of this method is that during probing and further exploration, the researcher could be sidetracked by information unrelated to the study. Nonetheless, to mitigate this, the researcher was guided by an interview guide that comprised a few open-ended questions that were flexible enough to be adjusted to meet the different contexts of each parent (Rubin & Babbie, 2017:465).

The advantage of using a semi-structured interview is its ability to capture rich data, which enabled the researcher to explore the participants' realities beyond surface-level responses (Rubin & Babbie, 2017:465). Open-ended questions like “What was your immediate reaction/emotion after learning about your child's diagnosis of ID?" allowed participants to express their emotions, thoughts, and coping mechanisms freely. This method fostered a conversational yet focused approach, making participants feel comfortable enough to share deeply personal experiences about their journey of caring for a child with an intellectual disability. The semi-structured interview covered a range of topics relevant to the study, ensuring that participants had the opportunity to share their experiences comprehensively.

The questions in the interview guide included:

- Parents' biographical details (e.g. housing, number of children)
- Parenting experiences (e.g. What are the most difficult parts of being a parent to a child with ID?)
- Psychosocial factors (e.g. Has religion played a role in how you have experienced caring for a child with ID?)
- Mental health (e.g. Have you ever had suicidal thoughts?)
- Resilience (e.g. Have you experienced any moments of personal growth or transformation through experiences as a parent of a child with ID?)
- Additional questions to clarify, where necessary, to ensure a deeper understanding of participants' perspectives.

To ensure the accuracy of collected data, a cell phone recorder was used to record all the questions from the researcher and answers from the parents. All participants were informed about the recording and had to permit before the recording started. Participants were informed about the recording process and were required to provide verbal and written consent to ensure ethical compliance. The researcher transferred the interviews to the researcher's laptop, which is password-protected. The recorded data was transcribed using Microsoft Word to conduct thematic analysis later.

3.6.3. Data analysis

The researcher used the reflexive thematic analysis (RTA) process to identify and analyse patterns in the data collected (Braun & Clarke, 2012 in Byrne, 2021:1392). Analysing data using reflexive thematic analysis takes the following steps: "Familiarising yourself with your data; generating initial codes; generating themes; reviewing potential themes; defining and naming themes and producing the report" (Nowell, Norris, White & Moules, 2017:4).

Step 1: Familiarising yourself with your data

It involves spending quality time with the collected data, e.g., reviewing the written notes (Byrne, 2021:1398). The researcher immersed in the data, repeatedly reading through interview transcripts and recordings and reflecting on the narratives shared by participants to comprehensively understand the data (Byrne, 2021:1398). This initial phase helped the researcher identify patterns and meaningful aspects of the psychosocial factors influencing parents' mental health. Additionally, the researcher wrote down any preliminary thoughts during the deep engagement with the collected data.

Step 2: Generating initial codes

During this phase, initial codes are produced from the data as the researcher revisits, interacts, and thinks about the data (Nowell et al., 2017:5). The researcher systematically coded the data both manually and digitally, using Microsoft Word and Excel, highlighting key phrases, sentences, and segments that reflected significant ideas. The data-driven codes captured elements such as emotional distress, financial strain, and social support.

Step 3: Generating themes

After identifying codes in step 2, the coded data extracts were sorted and collated into themes (Nowell et al., 2017:8). The researcher clustered codes that shared common meanings into a Microsoft Word and Excel document to generate potential sub-themes, which were later refined into main themes.

Step 4: Reviewing potential themes

Reviewing themes involves extracting the coded data for each theme for further refinement, i.e., determining if they form a coherent pattern (Nowell et al., 2017:9).
The researcher revisited the transcripts to ensure that the themes accurately represented participants' narratives and refined or merged themes where necessary; moreover, ensured that each theme was well-supported by the data. For example, participants often mentioned isolation and stigma, which are closely related; thus, they were merged into a single theme, “social challenges and exclusion” (Chapter 4 Theme 2).

Step 5: Defining and naming themes

Each theme is specified during this phase, and a story is written to tell a story. The theme name should immediately tell what the theme is about (Nowell et al., 2017:10). The researcher defined each theme by clearly articulating its significance and the specific aspects of parents' experiences. This step ensured that each theme contributed uniquely to understanding the research question (Byrne, 2021:1407).

Step 6: Writing the report

This phase begins when a researcher has established the themes and does a final analysis to write the report (Nowell, et al., 2017:10). A report is written and includes direct quotes to aid in understanding points of interpretation. Using participants' quotes to illustrate each theme, the researcher integrated the findings into the research report. The researcher engaged with the themes about existing literature, discussing their implications and drawing conclusions about the influence of psychosocial factors on the mental health of parents caring for children with IDs. The report involved rewriting and editing parts of the introduction and literature review.

3.6.4. Data quality

To ensure data quality, trustworthiness was established through the use of the following constructs and strategies as proposed by Guba (1981) in Nieuwenhuis (2020a:143):

Credibility

Credibility is described as ensuring the truthfulness and accuracy of findings (Nieuwenhuis, 2020:144). This means the study's findings should represent the parents' real meanings. The researcher engaged with the data deeply to understand the participants' perspectives. To increase trustworthiness, the researcher utilised peer debriefing with fellow students, discussed the progress of the research process with the researcher's supervisor, and discussed research decisions (Nieuwenhuis, 2020a:144; Schurink et al., 2021a:397).

Transferability

For the readers of the study to make connections concerning the research, the elements of the study, and their own experiences, transferability is the applicable construct to prevent generalised claims (Nieuwenhuis, 2020a:144). The researcher provided thick descriptions [as a strategy] of the context, participants' demographics, and key findings to achieve transferability. This will give any reader full and detailed context, participants, and the research design to understand and make their own decisions applicable to other settings (Maree, 2016:124). Although the study was context-specific, focusing on parents in Eersterust, the detailed descriptions would allow meaningful comparisons with other studies in similar communities. All findings were substantiated with relevant literature and guided by the ecosystem perspective as an established theoretical framework.

Dependability

Dependability refers to the thorough documentation of the research process. According to Nieuwenhuis (2020:144), it is established through the research design and its execution, the specific details of data collection, and a reflective evaluation of the study. This research ensured dependability by maintaining an audit trail and systematically recording all decisions made throughout the process, including developing themes and reflexive notes. Therefore, other researchers will be able to follow the step-by-step process of the study and replicate it or compare their findings with the study's findings, which enhances the study's dependability (Babbie, 2021:351).

Confirmability

In Nieuwenhuis (2020:145-146), Lincoln and Guba (1985) define confirmability as the participants' complete influence on what is found in the study, which means that the researcher's biases, interests, and motivations should not shape the findings of the study. To establish confirmability, the researcher used triangulation and audit trail as confirmability strategies by considering multiple sources of information, such as literature and participants' narratives, to ensure findings were grounded in the data rather than researchers' assumptions and documenting the entire research process and steps (Leedy & Omrod, 2019:269), respectively.

6.3.5. Pilot study

The researcher interviewed one participant who met the inclusion criteria for the main study, as it is recommended that a trial should be conducted on a small study before the actual (larger) study to test and validate the data collection method (Makofane & Shirinda, 2018:41; Strydom, 2021b:236). The researcher did a test run with one participant, implementing the data collection method, the interview schedule and the audio recorder to ensure it was effective and efficient. Thus, this allowed the researcher to make necessary changes and test the feasibility of the study before the main data collection started (Strydom, 2021:388). The researcher was able to rephrase some questions that the participant struggled to comprehend (Makofane & Shirinda, 2018:41). The participant who was in the pilot study was given an informed consent form (Maree, 2020:48). The pilot sample adequately represented the population of interest and was included in the main results.

3.7 ETHICAL CONSIDERATIONS

As far as human participants are involved, ethical considerations are vital, the goal being surety that no one will be harmed due to research activities (Babbie, 2017:63-64). Thus, the study was informed by the ethical research principles stipulated by Babbie (2017:62-72), Maree (2020:47-49), and Strydom and Roestenburg (2021:119-126). Before the study commenced, the researcher received ethical clearance from the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria with the help of the researcher’s supervisor. The researcher obtained permission from the Eersterust Care and Training Centre, where potential research participants were recruited. In addition to those mentioned above, the following ethical considerations will be observed:

Voluntary participation

Participants were not coerced/manipulated/forced to participate in the research study. Instead, they were given informed consent to sign as proof that there was no coercion, which contained the purpose of the study, the duration, risks involved, and benefits or loss of benefits (Babbie, 2017:63-66). Moreover, assurance that there were no consequences if the parent decided to drop out of the study (Fouché & Geyer, 2021:84). No participant withdrew from the interviews.

Informed consent

The participants received an informed consent form to read thoroughly and ask questions where necessary (Strydom & Roestenburg, 2021:122). The informed consent form contained the goal and objectives of the study, the nature of the study, possible risks associated with the study, and the potential benefits that might be gained (Maree, 2020:48). Before the interview began, participants provided both verbal and written consent to take part in the study and were given a platform to ask the researcher any questions or clarifications. In line with ethical guidelines, the data collected, including digital recordings, during the study will be retained; the researcher informed the participants that the data will be kept safely at the University of Pretoria for a period of 10 years. All informed consent forms are secured in a research file by the researcher.

Anonymity and confidentiality

Informed consent also binds the researcher from sharing the findings (Christensen, Burke & Turner, 2015:134). Data collection took place in a private space to ensure confidentiality. The researcher was given an office space to conduct the interviews to prevent any sensitive information from being heard (Abma, Banks, Cook, Dias, Madsen, Springett & Wright, 2019:58-59). Due to the nature of the study, the parents could not remain anonymous to the researcher. However, the researcher used pseudonyms to protect participants' identities. No unauthorised persons or organisations have access to participants' information.

No compensation for participants

To prevent inaccurate research results from being influenced, no participant received any form of compensation (Adler & Clark, 2015:91-93; Babbie, 2017:271). During the informed consent process, the researcher communicated to participants that no compensation would be provided for their participation in the study to prevent any possible inaccurate research results.

Deception

Participants were not deceived about the nature or any part of the research study (Padgett, 2017:79). The researcher clearly communicated the purpose, and goals of the research to participants in the informed consent process. Moreover, the information sheet contained all study aspects to the participants' awareness.

No harm (Debriefing)

One of the key principles is that research must not harm participants but, ideally, should benefit from it (Babbie, 2017:64). Only one participant indicated a need for a debriefing session that the researcher conducted herself. For the same participant, the researcher referred the participant to a social worker for additional counselling. The registered social worker, Ms. Melody Mudukuti, registration number 1057504, would have provided the counselling for free had the participant gone in for a session.

Gatekeeper

The researcher consulted with a gatekeeper to receive appropriate permission and conducted an ethically high-standard research study (Singh & Wassenaar, 2016:42-44). Ms Aurelia Hoods served as a gatekeeper in the study.

3.8 SUMMARY

Chapter Three outlined the research methodology employed in this study, along with the ethical principles that were strictly followed. The study was designed with a well-defined aim and achievable objectives. Additionally, the chosen research approach, type of study, research design, and methods were carefully selected and/or developed to align with the study's purpose and objectives. The research methods applied were effective, particularly in terms of sampling, data collection, data analysis, and maintaining data quality. Pilot testing was also successful, helping to resolve minor communication challenges and refine the interview schedule. Lastly, all necessary ethical guidelines were observed to ensure the research was conducted responsibly.
The next chapter delves into the empirical findings of the study.

CHAPTER 4: RESEARCH FINDINGS AND INTERPRETATION

4.1 INTRODUCTION

The research findings were collected by interviewing five participants who met the required inclusion criteria. The interviews were conducted face-to-face, recorded, and transcribed verbatim. The researcher analysed transcripts and coded data, where themes and sub-themes were identified. The biographical data collected from the participants is depicted in the column below, which includes age, gender, educational level, employment status, housing, and number of children. A reflexive thematic analysis of the research findings is presented and supported by verbatim quotes from the interviewed participants, literature substantiation, and interpretation from the ecosystem perspective.

4.2 BIOGRAPHICAL DATA

Table 4.1 shows the biographical data of all the interviewed participants using a semi-structured one-on-one interview schedule. Each participant was assigned a pseudonym to protect their identity as an ethical consideration requirement. The table displays information on the age, gender, educational level, employment status, housing, and number of children.

Table 4.1: Biographical information of participants

Participant	Age	Gender	Educational level	Employment status	Housing	Number of children
P(a)	35	Female	Not stated	Employed	Three-roomed house	2 children
P(b)	43	Female	Grade 12	Employed	Three-bedroomed house	1 child

P(c)	37	Female	Grade 10	Employed	Three-bedroomed house	2 children
P(d)	23	Female	Tertiary level	Employed	Four-bedroomed house	1 child
P(e)	54	Female	Grade 11	Unemployed	Three-bedroomed house	3 children

Table 4.1 reflects an overall view of the biographical data. This data is presented in detail below.

4.2.1 Age

The study consisted of five participants with an average age of 38.4 years, with ages ranging from 23 to 54 years. This shows a mix of young and older caregivers. Research indicates that younger parents in South Africa are susceptible to economic challenges (Statistics South Africa, 2021). In contrast, older caregivers may experience both physical and emotional exhaustion as a result of prolonged caregiving responsibilities, especially in communities with limited social and state support (Mphahlele, Makgahlela & Ramolobe, 2020:145-157), such as Eersterust.

4.2.2 Gender

All participants in this study were female, reflecting a global trend where mothers are the primary caregivers for children with disabilities. This burden of caregiving is largely carried by women in South Africa because of cultural norms and gender roles (Muthukrishna & Ebrahim, 2014:415-431).

4.2.3 Educational level

Participants' educational levels range from Grade 10 to tertiary education. Participants who only attained Grade 12 or less reflect the challenge in South Africa to access quality education, particularly in rural and township areas (Spaull, 2019:75-97). Consequently, lower educational attainment could hinder parents' ability to access and advocate for their child's needs.

4.2.4 Employment status

The following section presents the employment status of the participants.

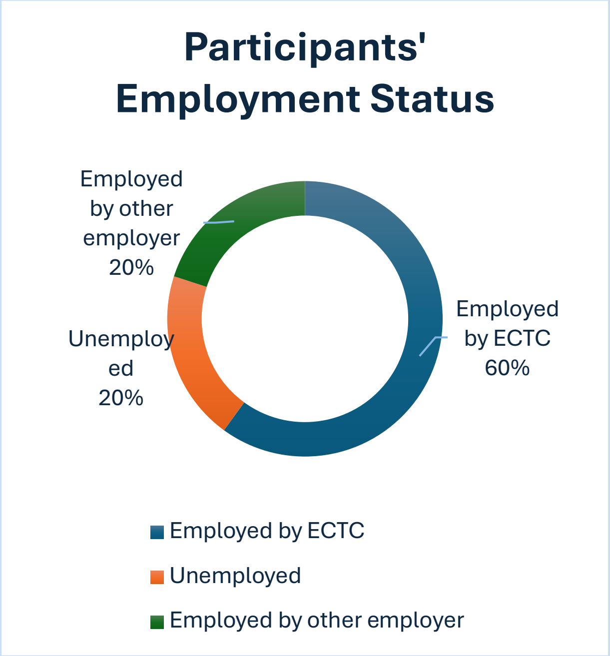


Figure 4.1: Employment status of participants

Only one participant from the study was unemployed; the Eersterust Care and Training Centre employed the majority of participants, and one was working at another company. It is evident how critical specialised institutions such as the Eersterust Care and Training Centre play a significant role in providing job opportunities for caregivers, especially in the disability sector. However, employed parents, especially those outside specialised institutions such as Eersterust Care and Training Centre, may experience work-life conflict if their workplace does not have policies that support parents of children with disabilities (Mphahlele et al., 2020).

From the ecosystem perspective, participants who worked at a specialised care centre, i.e., mesosystem level, likely provided participants a better understanding of intellectual disabilities as Eersterust Care and Training Centre specialise in serving the mentally and physically disabled in disadvantaged communities to the east of Tshwane as shared by Mrs. Aurelia Hoods, the principal of the centre.

4.2.5 Housing

The housing conditions of participants range from three-bedroomed to four-bedroomed houses, reflecting the socioeconomic background of the participants. Housing quality directly affects the well-being of children with disabilities, taking into consideration possible overcrowding and informal housing, which can worsen health and safety risks (Lund, 2020: 1-11).

Furthermore, access to sufficient housing, as in the case of the participants, indicates a structured and physically safe environment enabling them to take care of their children with IDs, thus resulting in a stronger microsystem according to the ecological perspective (Bronfenbrenner, 1992:191-195).

4.2.6 Number of children

The following section displays the family composition of participants during the time of the study.

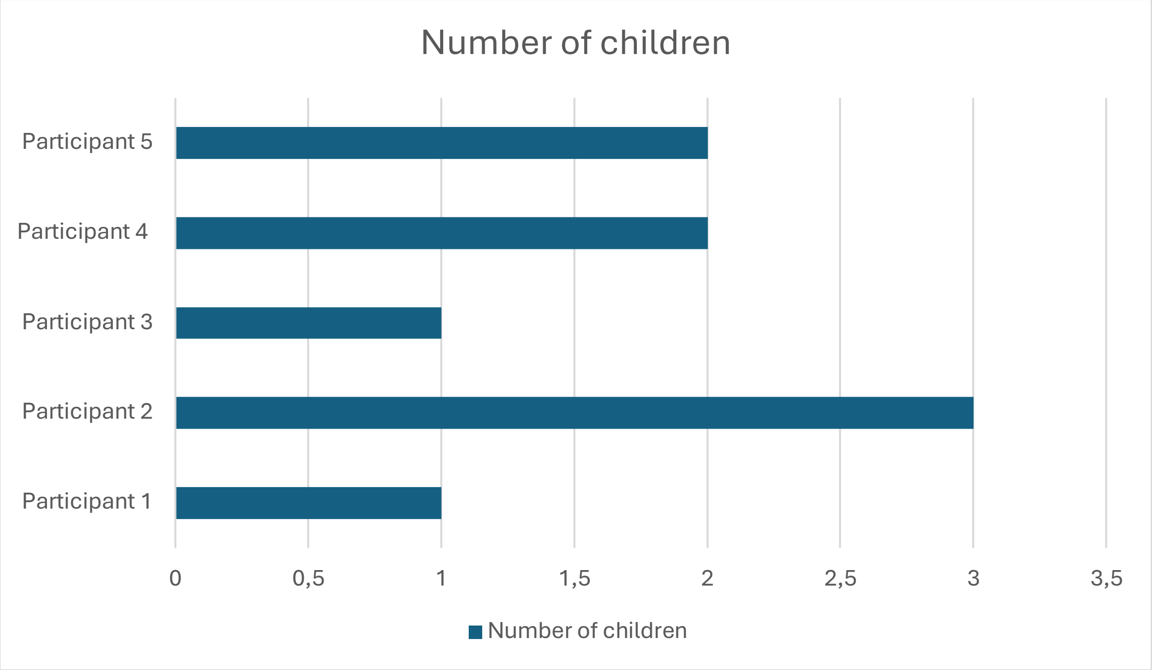


Figure 4.2: Number of children of participants at the time of the study

Two participants had one child, and another two participants had two children; then only one participant had three children. Thus, the mean number of children per participant was 1.8 during the time of the study.

From the ecosystem perspective, parents with multiple children face increased caregiving responsibilities within the micro level (Bronfenbrenner, 1992:191-195). Studies in South Africa highlight that the more children in a household, the higher the possibility that a child with a disability will receive less individualised attention, which can impact their developmental progress (Muthukrishna & Ebrahim, 2014). Thus, this can lead to emotional strain on both the parents and other siblings within the microsystem.

This section presents the biographical characteristics of the participants at the time of the study. The following section will provide an in-depth discussion of the themes and sub-themes that emerged during data analysis.

4.3 REFLEXIVE THEMATIC ANALYSIS

In the table below, the themes and sub-themes that were generated during the data analysis are depicted.

Table 4.2 summarises the themes and sub-themes generated during the data analysis.

Themes	**Sub-themes**
Theme 1: Emotional and psychological impact	*1.1: Feelings of denial and acceptance struggles following diagnosis* *1.2: Fear for the child's future* *1.3: Emotional exhaustion, fatigue, and burnout*
Theme 2: Social challenges and exclusion	*2.1: Stigma and judgement* *2.2: Avoidance of social settings* *2.3: Lack of awareness in the community*
Theme 3: Financial strain	*3.1: Costs of diapers and special diets*
Theme 4: Parenting challenges	*4.1: Behavioural challenges*

	✓ *Aggression and disobedience* ✓ *Challenges with social and emotional expressions* *4.2: Navigating traditional and cultural beliefs*
Theme 5: Coping Mechanisms	*5.1: Reliance on faith and prayer* *5.2: Family support* 5.3: *Coping through distractions and emotional control*
Theme 6: Positive aspects and personal growth	*6.1: Celebrating a child's strength* *6.2: Increased awareness and understanding*
Theme 7: Suggestions and recommendations	*7.1: The need for community support* *7.2: Promoting awareness and a positive attitude toward intellectual disabilities* *7.3: Improving access to resources and services*

The researcher utilised alphabets to create pseudonyms for the quotes to support themes and sub-themes. The pseudonyms assigned are **P(a), P(b), P(c), P(d), and P(e),** which represent the participants; however, they are not in the chronological sequence as they appear on the biological information (Table 4.1). This ensures that the participants' identities are protected, maintaining confidentiality. Pseudonyms such as P(a) son or daughter were used for male and female children in quotes where participants mentioned their children. Each theme and its sub-theme are discussed in depth below.

4.3.1. Theme 1: Emotional and psychological impact

Participants shared the emotional and psychological rollercoaster they experienced while parenting a child with ID. This theme was derived from an exploration of the participants' parenting experiences concerning how they feel about caring for a child with ID and how their children's condition affected their emotional well-being, including any anxiety, depression, or stress they may have experienced. The sub-themes emanating from this theme were feelings of denial and acceptance struggles following diagnosis, fear for the child's future, and emotional exhaustion coupled with burnout as they cared for their children with IDs.

4.3.1.1. Sub-theme 1.1: Feelings of denial and acceptance struggles following diagnosis

This sub-theme focused on the feelings of denial and acceptance struggles following the child's diagnosis. The responses of the participants showed that denial and non-acceptance became their first emotional response after receiving their child's diagnosis of ID.

> ***P(a):*** *"..there was this nurse, she came to me and she asked what was wrong with me and if I knew the condition of my child, and I was like yes, I told her I did know. Then she asked me if I accepted the condition of my child. I was like, no, I don't accept it. I was like what are all the people, my family going to say about it and then she told me that I mustn't worry, everything will be fine, but is gonna start with me first to accept my child then I did it and from that moment he was fine he didn't go to the hospital that much anymore except for operations"*
>
> ***P(b):*** *"Maybe they don't do their work at school or something like that. I couldn't take it."*
>
> ***P(d):*** *"Accepting, you know, one day you accept that your child is like this and then the next day you wake up and you realise that you're still in denial, right? So, I feel like the one thing that hits me the most is accepting that my child is like this. Like, I accept for a month; and then the next month, and then again, I'm down. I'm like, oh my God, my son is like this. What am I going to do? What's going to happen? You know, how can I try to improve him? How can I try to help him? hey, yeah, I'm like, and also accepting in terms of, I don't know what I'm going to do with the son. I'm like, I just wish he could be normal. You know, I just wish the next day he could wake up and be normal and act normal. So yeah, I think accepting is, yeah, it's one of the big things."*

The discussion between P(a) and the nurse indicated that the participant did not accept her child's condition. The new information about the diagnosis led P(b) to question the adequacy of the diagnosis when she was told. Another participant went through an oscillation to accept the condition of her child. These reactions align with the two stages within the five stages of grief by Kubler-Ross (1969), namely, denial and acceptance, as outlined by Tyrrell, Harberger, Schoo, and Siddiqui (2023:2-3). Kubler-Ross (1969) noted the shock of receiving a terminal diagnosis from patients and the rejection of the reality of the information, which is a common defense to protect oneself and to process the reality of a condition (Tyrrell, et al., 2023:2). Acceptance is described as a gradual adaptation, however is often a nonlinear process marked by regression as found during a study of Asian and non-Asian American parents of children with developmental disabilities (DeLambo, Chung, & Huang, 2011). This is complemented by one of the participants' descriptions of accepting one day and the next day regressing.

From the microsystem and macrosystem levels, according to the ecological systems theory (Eriksson et al., 2018:419), closest connections and societal and cultural factors, respectively, play a significant role in the participants' denial and acceptance struggles. For instance, a participant highlighted the interaction with a nurse and her concerns about societal (macrosystem) and family (microsystem) judgment, which could complicate the acceptance process.

Thus, this theory supports the assertion that parents' feelings about their child's diagnosis are shaped not only by their perceptions but also by the broader systems they interact with.

4.3.1.2. Sub-theme 1.2: Fear for the child's future

This sub-theme focused on the participants' fears they embodied concerning their children's future as they live with IDs.

> ***P(d):*** *"...and I was already thinking, oh my God, what am I going to do? How am I going to live with a child like this? Like what I was already thinking of the future, will he be able to, you know, help himself in the future?... I'm afraid that when he grows up, he will never understand what's happening in the world the world that we live in is very cruel. So I just pray."*
>
> ***P(a):*** *"To be honest, I wish to grow old with him… to grow old with him. I really wish to grow old with him. I just want to be there in his life and support him, I*

> *just want to take care of him… I will take care of him for the rest of his life. For me, I'm just praying to God to give me the strength to still look after him"*
>
> ***P(e):*** *"Okay, Uhm… you know what? In my mindset I (P(e) son name mentioned), he won't be able to look after himself in the future, so he is going to need someone who can look after him because he can work, he can do things, but he can't think on his own what is right what is wrong you see; because she doesn't know what is going to happen with the children when I'm dying."*
>
> ***P(b):*** *"What I wish, I wish children with wish for that cause, maybe if I can pass on what's gonna happen to him, cause I'm afraid even to get sick."*

Among the participants, a collective response revealed a profound fear for their children's future with IDs, and they were concerned about how their children would survive in the world. A study on parenting and future anxiety of parents with children with developmental disabilities found that these parents reported stronger feelings of "pessimism about the future" (Bujnowska, Rodriguez, Garcia, Areces & March, 2019:2). Thus, parents perceive the world as unsafe for their children, which then amplifies their anxieties. During the interview, a participant described the world as cruel.

Another concern for their children's future was the uncertainty after the participant's death. An exploratory study conducted by Burke, Rios, Aleman-Tovar, Arnold, and Owen (2020:1265) highlighted that 38,58% of parents were uncertain who would fulfil the caregiving roles of their children after their death, and 10,23% reported having no one to take on future caregiving. Thus, this uncertainty causes extensive fear for parents about their children. Hence, a participant wished to grow old with her child, also expressing her reliance on spirituality to cope with the fear, which is discussed under Theme 5: Coping mechanisms.

The macrosystem of the ecological systems theory perfectly explains parents' fears for the future of children with IDs. The macrosystem includes the broader society and culture that shape individuals' experiences, including policies, societal attitudes and norms, cultural values, and traditions (Cherry, 2023). Hence, most participants' fears centred around societal inclusion and whether their children would have opportunities for independent living. Research shows that society's view (including stigma and judgement) toward disabilities can significantly impact parental stress (Cheng & Lai, 2023:4); this is discussed in detail under Theme 2: Stigma and judgement. Furthermore, one participant was concerned about financial security, wishing her child to secure permanent employment, which is influenced by the exosystem level, which addresses components such as community resources (Cherry, 2023; Bronfenbrenner, 1994:1646).

4.3.1.3. Sub-theme 1.3: Emotional exhaustion and burnout

This sub-theme section focused on the emotional exhaustion and burnout experienced by participants as they cared for their children with IDs.

> ***P(b):*** *"At first, joh I couldn't take it, it was so stressful, depressed, headaches, asking myself why"*
>
> ***P(a):*** *"I wasn't prepared, Joh, I was like crying for months and then he would get very sick, like we were in the hospital week after week after week…"*
>
> ***P(d):*** *"So emotionally I wouldn't say that I am okay, I'm not an yeah, even today there are times where I just cry…. I don't know how to handle this, and it's just a lot. So, when it comes to emotional I don't think I will ever be okay, some days I'm just good, some of the days I am not. IT has been like that and its still like that. So yeah… Yeah like I just wanted not only rest my body, but I just wanted also my mind to rest. Unfortunately, my mind couldn't rest but I just wanted to, I felt like I wanted my body to just switch off everything just switches off for like that day and then I will come back the next day, that's what I wished would happen… Because being a mother with a child with autism, it's also draining"*

Parents of children with IDs experience elevated levels of stress, anxiety, and depression compared to the general population (McConnell & Savage, 2015:100) compared to parents of typically developing children. The description of one of the participants stating they experienced headaches, stress, and depression aligns with this finding. Participants also mentioned the frequent and/or prolonged crying exacerbated by their child's ID. One participant stated that she wished that her body and mind could switch off, as it was draining for her to have a child with ID. These findings align with the literature by Masulani-Mwali et al. (2018:1-3), who found increased anxiety, stress, and/or depression as the result of caring for a child with ID. Furthermore, Azeem et al. (2013:290-292) found that 77% of mothers with children living with IDs suffered from anxiety and/or depression.

Through the lenses of the ecological perspective, it is evident that daily direct interactions with the child (with IDs), which come with unique challenges and stresses, could have an impact on the participants' microsystem, as the nuclear family must now adapt to changes as the child becomes dependent on the parent (Bronfenbrenner, 1992:191-195), thus, increasing parental exhaustion (Azeem et al., 2013:290-292). Moreover, this can overflow into the participants' mesosystem as the frequent emotional reactions, i.e., crying a lot, could cause participants to avoid other people and, as a result of isolation, could have a negative impact on relationships outside their nuclear family (Perron, 2017:198-200). Social isolation is further discussed under sub-theme 2.2.

The previous theme discussed the emotional and psychological challenges faced by participants, including feelings of denial and acceptance struggles following diagnosis (sub-theme 1.1), fear for the child's future (sub-theme 1.2), and emotional exhaustion coupled with burnout (sub-theme 1.3) as they cared for their children with IDs. The next section will take a look at theme 2.

4.3.2. Theme 2: Social challenges and exclusion

This theme was derived from exploring the societal challenges that participants faced in caring for children with IDs, which included stigma and judgment, avoidance of social settings, and lack of awareness in the community.

4.3.2.1 Sub-theme 2.1: Stigma and judgement

This sub-theme discusses the stigma and judgment the participants experienced as parents caring for children living with IDs.

> ***P(e)****: "People laugh at him, and children his age…they think Diego must act normal and it's very difficult I don't know how to explain, and that is things that make me cross, even people from outside they also say that to me and I say it makes me cross."*
>
> ***P(d)****: "…people will, like, look at you, you know, like this, like your son is crazy, and some of them really, they think kids like this are crazy, you know, they are out of their minds and stuff like that. So, it's very hard to be a mother in such an environment that people don't understand autism, you know, because you also feel judged a lot, right?"*

> ***P(a):*** *"Like for me, it's better for me to be around him than to be with other people."*
>
> ***P(d):*** *"And when it comes to the dating world, you are always scared… I'm like, is the person going to accept my son and understand and love?... I'm like, you know what, it's not worth it because either way, it's not like this person is going to understand my son and love my son and whatnot. I feel like I always say, they want to be stepfathers to normal kids.*

Name-calling such as "crazy" as shared by a participant, the stares, others laughing at the child with ID, and the societal expectations that children with IDs should "act normal" described the emotional toll on the participants as they were judged and stigmatised by society due to their child's disability (Mitter et al. 2019:3-5). One of the participants deemed it as a solution to remain close to her child rather than to expose herself to societal judgment. There was also the fear of engaging in romantic relationships with fear of being judged and whether the participant would be accepted with a child with ID, as the participants believed that men could only be involved with them if the child was "normal". According to Mitter et al. (2019:4), this participant experienced self-stigma as one of the four forms of stigma. In contrast, the majority of participants reported public stigma, which is the societal attitudes directed towards the stigmatised family, encompassing both the parent and the child with an intellectual disability (Mitter et al., 2019:4).

Through the lens of the ecosystem perspective, the issue of people laughing and staring at children with ID and the challenges faced in the dating world for parents fit within different levels of Bronfenbrenner's Ecological Systems Theory. Cultural beliefs (macrosystem) play a significant part where children with IDs are devalued and stigmatised as "crazy" and less capable, due to negative societal attitudes (Emerson & Hatton, 2007). Participants also experienced their children being laughed at in the community/society, as interactions between the family and other social structures contribute to stigma reinforced or challenged (Werner & Scior, 2016), thus parents can feel unsupported due to a lack of stigma addressed, leading to isolation.

From the exosystem level, the misrepresentation or underrepresentation of IDs in social services, media, and policies further contributes to stigma. For example, negative stereotypes from the media can lead to misconceptions and societal bias (Corrigan, Powell & Michaels, 2012). However, increased rights movements and laws, such as the Children's Act 38 of 2005 and the Convention on the Rights of Persons with Disabilities (CRPD), contribute to improved awareness and protections over time (chronosystem).

It is important to note that the sub-themes under social challenges and exclusion are interconnected. It is almost like a cause-and-effect relationship where it could be suggested that the stigma and judgment faced by parents of children with IDs often stem from a lack of disability awareness (Scior, Mcloughlin, & Sheridan, 2015), which is discussed under sub-theme 2.3. Subsequently, parents caring for children with IDs may avoid social settings due to fear of judgement, as Ali, Hassiotis, Strydom & King (2012) suggested.

4.3.2.2 Sub-theme 2.2: Avoidance of social settings

As mentioned above, this sub-theme focuses on the withdrawal/avoidance of social settings by parents caring for children with IDs.

> ***P(d):*** *"So it is very hard to go outside with your child, go to gatherings, go to malls, because when they start reacting or when your child starts acting different,"*
>
> ***P(a):*** *"I get irritated when people still ask me why is he still like this, will he ever do that, will he ever do that. So, for me I isolate myself from the outside world."*
>
> ***P(c):*** *"I was even ashamed to walk with him in the street… For me, most of the times, sometimes there's something you must, like people, they are asking you, come, let's go to the party and stuff. You can't go because you have a challenge at home. So, you can't explode yourself and go out with your friends and people."*

Participants found it hard to engage with others, highlighting the judgment and a lot of questioning about a child's abilities in public spaces. This withdrawal can limit access to supportive networks, leading to detrimental effects on their mental well-being (Chithambaram, Corby & Rajendran, 2024:9-10). Another crucial point, as stated by Baumgardner (2019:230), is that some parents isolate themselves from social settings because they are homebound and are the only ones caring for the child with ID. This supports the expression of two participants who could not attend gatherings such as parties and shopping malls because they were the only caregivers.

From an ecological perspective, the immediate environment (microsystem) and extended families (mesosystem) can be affected as parents are constantly not participating in family gatherings. The expectations or the frequent questioning could hinder participants' social participation as they might have feelings of discomfort or shame, which aligns with the findings suggesting that social exclusions are due to perceived stigma (Baumgardner, 2019:230).

4.3.2.3 Sub-theme 2.3: Lack of awareness in the community

This sub-theme focused on the lack of community awareness about IDs contributing to the stigma and judgment experienced by parents caring for children with IDs.

> ***P(d):*** *"Yeah, one thing I've learned is that our society and, okay, yeah, our society and people our age, most of them, they don't understand these things. They don't have knowledge on different disabilities."*
>
> ***P(b)****: "Like my friends they are surprised sometimes that how come you say your child is like that he seems fine, and I say yes he seems fine but he has difficulties in learning that why he is not going to the normal school, he is going to the special school. Even my aunt was like no man, but he is fine, yes he is fine and you even tell him what to do and send him to the shop and everything that you need, he has his difficulties because he also has a learning disability."*
>
> ***P(a): "****It affects me badly because I think most of them, they are not educated about certain disabilities."*
>
> ***P(c)****: "I can say from my point of view, I think for, don't look at other people's children like this. It can happen to you also. You can have also the same kids, so don't look at that one like It's not a human. It's like that was the challenge for me."*

Participants expressed that people in their communities are not educated about different disabilities. The perception that a child "seems fine" but struggles with learning reflects how IDs can be misunderstood when not physically apparent, as expressed by a participant. Another participant suggested that people could believe that IDs only affect others, thus feeling judged by how people look at their child. Therefore, to foster empathy and support for parents of children with IDs, a study emphasises the importance of educating communities on disabilities (Duran & Ergun, 2019:394-395).

The ecological perspective on the lack of awareness about IDs in the community indicates a need for awareness from the microsystem level, as participants expressed frustration that friends and families do not understand their children's conditions, which extends to the Chrono level, as one participant stated that people her age are not knowledgeable about IDs. From a macro level, there is a call for promotion and support to empower people with disabilities, as stated by pillar four of the White Paper on the Rights of Persons with Disabilities (RSA, Ministry for the Department of Social Development, 2016).

This theme stipulated the social challenges that parents caring for children with IDs face in their day-to-day lives, including stigma and judgment (sub-theme 2.1), avoidance of social settings (sub-theme 2.2), and lack of awareness in the community (sub-theme 2.3). From the ecosystem perspective, the highlighted emotional toll on parents, including isolation or reluctance to engage socially, could affect the mesosystem relationships (Bronfenbrenner, 1992:191-195) of parents, showcasing the importance of addressing societal misconceptions and promoting inclusivity. The next section will discuss theme 3.

4.3.3. Theme 3: Financial strain

This theme was derived from exploring the financial challenges experienced by parents caring for children with intellectual disabilities. Financial strain emerged as a stressor for the participants as they struggled to afford specialised diets and aids for their children, the main and only sub-theme under financial strain.

4.3.3.1. Sub-theme 3.1: Costs of diapers and special diets

The costs of diapers and special diets are the only main sub-theme under the financial strain experienced by the participants.

> ***P(c):*** *"Oh, oh, oh. The eldest Diapers sho It's a lot. You can see that's us is going for Diapers also. Because it's very expensive. The eldest Diapers are the most expensive."*

> ***P(b)****: "At home also he eats this, he doesn't eat that, you know you need to buy specific things so that he will be able to eat them or make food for himself, so the challenges were financially, on his father's side, he was not there"*
>
> ***P(a)****: "he has changed from baby diapers to adult diapers, which is very expensive… also the fact of tube feeding, so every time, I can only buy maybe a blender that is maybe R300, I can't buy the other one which is a R1000 blenders that you buy for R300, they break maybe within 2 to 3 years, then you need another one."*

Most participants had financial challenges, as their children demanded costly adult diapers, specific food different from what the participants eat, and feeding aids such as tubes and blenders, considering that some participants depend on single incomes. At the same time, one is unemployed, and the majority are single parents. Research suggests that this financial strain is increasing as high "out-of-pocket" costs, such as the cost of special foods and home modifications, are required for children with special healthcare needs (Pilapil, Coletti, Rabey, & DeLaet, 2017:193). This underscores the financial impact of caregiving, which could add to the overall stress experienced by caregivers.

Applying the ecosystem approach, it is evident that high food costs and other costs related to individuals living with IDs could have significantly influenced household budgeting as the immediate environment, thus possibly exacerbating parental stress (Bronfenbrenner, 1992:191-195).

This previous theme highlights the significant economic challenges parents of children with ID face. The primary financial burden stemmed from the costs of essential items such as diapers, specialised diets, and feeding aids, which strained the household budget, thus impacting the families on a micro level (Bronfenbrenner, 1992:191-195). On a broader level (macrosystem), economic factors such as high costs can further influence the caregiver's experiences (Mbedzi, 2019:95-99).

The following section will take a closer look at theme 4.

4.3.4. Theme 4: Parenting challenges

This theme was derived from exploring parenting challenges experienced by participants as they care for children with IDs. It has been found that parents caring for children with IDs face unique challenges as compared to parents with neurotypical children under their care (Peer & Hillman, 2014:93-94; Mitter et al., 2019:10-15). The sub-themes that emerged from this theme include behavioural challenges and navigating traditional and cultural beliefs, which are discussed below.

4.3.4.1. Sub-theme 4.1: Behavioural challenges

The sub-theme focused on the behavioural challenges experienced by the participants, categorised into two behavioural challenges, i.e., aggression and disobedience, and challenges with social and emotional expressions.

“Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities” are defined as challenging behaviours (Emerson 2001 in O'Regan, et al., 2022:20).

- ***Aggression and disobedience***

P(e) was teary when she expressed her distress due to the child’s aggressive behaviour:

> *“It's like, he's just getting out of control. It's like, every season, he has the time to get mad. Then he hits me, he wants something, and if I don't want to give it to him. He hits me, he swears at me, he's got bad manners, he backchats me. So, I don't know what to do. Like, at this moment, I'm stressing because he's not listening to me. And this morning, my husband said he's going to send him away because he doesn't have manners. And I'm so scared of him because sometimes when he's in that position and he hits me, it's bad. It's like, he can even kill me without knowing what he's doing.”*

P(b): “*One day he is angry, the other day he is fine, the other day he is so sweet, sweet, sweet, yeah, but the only thing that we fight for is water, he likes using water even when it’s cold.”*

- ***Challenges with social and emotional expressions***

  P(e)*: “So, he doesn’t show emotions… When someone passes away in the family, he’s not crying. Yeah, he’s not saying anything”*

  P(d): “*My son will just shout out of nowhere, and people will just stare at me like I am not disciplining him as I said. He will just shout, and people will like look at you, and sometimes when he's in the car, he doesn't want to sit still.*”

Aggression, coupled with disobedience and challenges with social and emotional expression, were the main challenges experienced by the participants. One participant even cried while she was sharing about how she was beaten by her child with ID, and there was nothing she could do because she understood that it was not on purpose, but a reaction. Studies have observed that children with IDs are at risk and frequently present challenging behaviours such as aggression, social and attention difficulties, withdrawal, destruction of property or self-injury, and anxiety (Hofmann & Muller, 2022: 353-354; O'Regan, et al.,2022:20). Therefore, it is not surprising that participants reported one or more of these challenging behaviours in their children with IDs.

All participants have direct interactions (the microsystem level) (Bronfenbrenner, 1994:1645-1646) with their children with IDs, where they constantly deal with a child’s aggression or emotional struggles, which have led others to even blame themselves or question their parenting styles, which could also be influenced by societal expectations within the macrosystem level (Bronfenbrenner, 1994:1646). Thus, parenting challenges relating to aggression, disobedience, and social-emotional challenges could significantly affect parents' mental health when analysed from the ecosystem perspective.

4.3.4.2 Sub-theme 4.2: Navigating traditional and cultural beliefs

The following sub-theme discusses the challenge of navigating traditional beliefs as a caregiver to a child with ID, as experienced by participants:

> ***P(d):*** *"Mm-hmm. Oh, they'll tell you, um, maybe your son, you must take your child to the father, the side of the father's family. They must, uh, you know, do a traditional ceremony, you know, and those things will go away, you know, or they would, they would, yeah, that's the main thing. That's the main thing I hear every time. Like, no, I, this thing, you must just do that. You will see the next day your child is going to wake up talking, you know, it's going to be normal. Or maybe they must give him a name. They must give him a name. There's a name that they must give him things like that."*
>
> ***P(e):*** *"...so I was taking sleeping pills while I was pregnant… I didn't know I was pregnant so that affected the child's brain… yeah, in a way I blame myself but on the other side I say, God, this is what you gave me, and I must stay with it, i must look after it"*
>
> ***P(a)****: "Yeah, normally people would say the child with disability has been bewitched, and I don't think so, I think God gave you that, it's like a blessing. It's a blessing in disguise."*

Culture and traditional beliefs have also played a role in the participants' lives. One highlighted that her family holds a cultural perspective that a traditional ceremony is the solution to her child's condition and a means to "cure" her child. Contrarily, two participants challenged this perspective as they expressed a more faith-based interpretation. One participant rejected the notion of witchcraft and viewed the child as a blessing in disguise from God. In contrast, another participant believed that it was God who gave her the child, but also blamed medication taken during pregnancy as the cause of ID in her child. These beliefs are common in most African countries where traditional interventions are sought before professional or medical help, where disability is viewed as either a curse or a gift (Classens et al., 2018:147).

From an ecosystem perspective, it is evident how families from a microsystem level can influence a caregiver to follow traditional rituals such as naming ceremonies instead of seeking medical and/or therapeutic interventions. This can put pressure on the caregiver, especially when the caregiver does not believe in traditional explanations, however, to conform to given values and avoid stigma or discrimination (Eskay, Onu, Igbo, Obiyo, & Ugwuanyi, 2019: 475-476; UN, 2018) it can become mentally exhausting to balance family expectations and medical advice from a mesosystem level. Faith-based interpretations could hinder caregivers from accessing medical interventions from an exosystem level as they view the child as a divine blessing, thus affecting their openness to medical intervention or alternative treatments, as discussed by Murphy and Gabbay (2015: 125-131).

The previous theme presented parenting challenges, including behavioural challenges (sub-theme 4.1) and navigating traditional and cultural beliefs (sub-theme 4.2), which cause distress among caregivers, aligning with research that highlighted the high prevalence of challenging behaviours in children with IDs (Hofmann & Muller, 2022; O'Regan et al., 2022). Moreover, cultural and traditional beliefs can further complicate caregiving.

From an ecological perspective, parents face direct stress in their microsystems, whereas societal expectations (macrosystem) and family influence (mesosystem) can either support or hinder the parenting journey (Bronfenbrenner, 1994). Faith-based beliefs may also limit access to professional help (exosystem) (Murphy & Gabbay, 2015). The following section looks deeper into theme 5.

4.3.5 Theme 5: Coping Mechanisms

The fifth theme was derived from exploring the various coping mechanisms participants utilise to deal with ID-related challenges. The sub-themes that emerged from this theme were: reliance on faith and prayer, family support, and coping through distractions and emotional control.

4.3.5.1 Sub-theme 5.1: Reliance on faith and prayer

This sub-theme focuses on the reliance on faith and prayer as a coping strategy, as stated by the participants. This was derived from discussing participants' resilience concerning caring for a child with ID.

> **P(e):** *"I pray. I pray, you know what, we like church. And we are like Christians, like to go to church and like to pray. I think with God's help, every day of my life. I'm going through all the situations"*

> ***P(b):* "***Yeah. It does help, it does help because we do go to church on Sunday, he also like church, yeah he likes going to church even when I'm not going, he will tell me, "Mommy I'm going to church, what time is it? Should I wake up? should I bath now?" and I say yes you can go"*

> ***P(c):*** *"For me and myself now, in the beginning I was more down to earth. And I told myself, hayi, man, just lift up your hands and face the world. The devil is there. God is with you."*

> **P(a)**: "*Religion, we got to church, and like for me to go to church, I feel like sometimes I don't get the support... Not like I want money from them or something, I don't get support from my church to raise him in the church. So, I do go, but not regularly, because I feel like I don't get support from the church."*

The responses from the participants indicated that going to church, faith, and prayer are significant coping mechanisms for them in navigating parenting challenges. However, one participant, though she sometimes participates in religious activities, i.e., going to church, still sees a void in terms of the church members offering support thus, it gives mixed experiences though her belief in God helps to cope, but lack of tangible support from the church could diminish the spiritual practice as a coping resource. Nonetheless, according to Pargament (1997), prayer and faith are spiritual resources, strengthening one to endure hardships.

In the context of the ecosystem perspective, these findings reflect the connection between the families and the church, which creates a mesosystem (Evans, 2023). The mesosystem consists of connections between settings such as home and religious institutions (Bronfenbrenner, 1992:191-195); in this case, the church is a key social support structure that reinforces the participant's coping strategies. From an individual level (microsystem), the participant's faith and prayer practices provide strength and resilience for them.

4.3.5.2 Sub-theme 5.2: Family support

This sub-theme highlights the role of family members in the participants' lives as coping mechanisms, as participants care for children with IDs.

> ***P(e)****: "Sometimes I cope because my husband and the middle one in the house are helping me a lot."*
>
> ***P(d):*** *"…when it comes to my family, they're very protective and supportive, very supportive and very loving, especially towards my son. I never expected them to be so supportive and understanding of my son. But yeah, my mom gets my son, so yeah."*
>
> ***P(b):*** *"It's my boyfriend. He supports me very, very much. He understands cause I started to date while my son was 3 or 4, so we went through the journey together, and I was explaining to him that this is the situation, this is what's happening, the reason why I do to Steve Biko all the time is this and this and that."*
>
> ***P(a): "****…and then know some of the people who don't get support from their families, so I do get support from my mom and my dad, I would say mostly support."*

As stated by participants, there is a balance of support between family members and partners/spouses. One participant was even astonished by the tremendous support she received from her family, especially her mother. Another participant is supported by a boyfriend (stepfather figure) who came into the participant's life. At the same time, her child was young and had to explain their trips to a health facility in connection with the child's treatment plan. Family support is recognised as a protective factor for parents with children with disabilities, alleviating psychosocial (parental) stress (Morrison, 2023:25-27). However, a lack of family support can lead to burnout, depression, and stress among parents raising children with disabilities (Woodman, Mawdsley & Hauser-Cram, 2015). Thus, effective support from family members and partners/spouses could have helped participants deal with ID-related stressors.

The most relevant level of the ecological perspective is the microsystem, which includes an individual's closest relationships (Bronfenbrenner, 1992:191-195). Since participants stated boyfriends, spouses, and parents as sources of support, the microsystem is the most appropriate level.

4.3.5.3 Sub-theme 5.3: Coping through distractions and emotional control

The following sub-theme focuses on using distractions and controlling emotions to cope with challenges, as reported by participants. This sub-theme was derived from discussions with participants, where they disclosed that shopping, spending time with family, and managing emotions helped them deal with the stress of caring for a child with ID.

> ***P(e)***: *"Yoh yeah when I was depressed and stuff like that then I went to the shops and I buy yeah this is what was...to go to the shop was helping me even though I don't have money, I tell my daughter let us go to Menlyn, we don't buy anything we just go there and get something to eat maybe ice cream, sometimes when we are hungry we have our food or whatever yeah. If there is something on my account, I will finish that account. So yeah, that was one of the things that helped me cope, to go and shop, yeah."*
>
> ***P(d):*** *"Coping strategies. Eh I don't have. I only have one thing which is, 'you should be strong' that's the only thing I have. I have no coping strategies. The moment I think of crying, I'm like, 'Stop it, you need to be strong. There is no time to cry, there is no time to act like a baby, you are now a mother, you have to be strong. Every challenge that comes your way you have to take it like a mother, you need to take it as a grown woman'. So, I don't have, apart from eating a lot I don't have any strategy."*

Using the categorisation of coping strategies by (Peer and Hillman (2012:47), it is evident that both participants engaged in emotion-focused coping where one used shopping or leisure activity and another participant suppressed and/or controlled emotions to help them escape their stressors (Compass, Jaser, Dunbar, Watson, Bettis, Gruhn & Williams, 2017:91-96). Nonetheless, though these coping mechanisms can provide temporary relief from ID-related stressors, unresolved emotional stress can accumulate over time (McConnell et al., 2014:833-848).

The microsystem level of the ecological systems remains the most relevant as it encompasses the participant's personal environments and behavioural habits that directly impact how they manage stress (Bronfenbrenner, 1992:191-195).

This previous theme showcased the various coping mechanisms used by participants, including faith and prayer (sub-theme 5.1), family support (sub-theme 5.2), and coping through distractions and emotional control (sub-theme 5.3). From an ecological perspective, these coping mechanisms operate primarily within the microsystem (close personal relationships) and mesosystem (connections between family and religious institutions) (Bronfenbrenner, 1992:191-195).

The following section will look into theme 6.

4.3.6 Theme 6: Positive aspects and personal growth

The sixth theme that emerged from the interviews highlights the positive aspects and growth of parenting children with IDs. Participants shared meaningful experiences and personal development that shaped their journey as parents of children with IDs. The two key sub-themes that emerged from the discussion are celebrating a child's strength and increasing awareness and understanding.

4.3.6.1 Sub-theme 6.1: Celebrating the child's strength

This sub-theme highlights the reflections from the participants who acknowledged and took pride in their children's capabilities and potential.

> **P(d)**: *"…when I look at my son and the things that he does, especially when it comes to technology, using my phone, my son is very smart with technology, and I feel like that specific part will work for him in the future. You know technology is the world. The technology is the future right now. And I'm thinking, and I'm looking at my son like this, this person is very smart when it comes to technology"*
>
> ***P(b):*** *"Mmm. He amazes me each time. He amazes me every day because sometimes he wants to help me with cooking, and I say aw, do you know how to cook, and he says yeah, I can. And he likes also baking and I don't know how to bake, I don't know how to bake, I don't like baking in fact, but he knows"*
>
> ***P(c):*** *"Yeah, because for me, for Jay, he can crawl a lot, and then he's helping me when I'm starting to put him on the bed. And then he will lift him up and carry on, and then he will turn himself. That's the positive one for me for part-time"*

Participants shared the unique strengths that their children exhibit. One participant highlighted technology proficiency in her child; another one highlighted her child's interest in culinary. According to Grynszpan, Weiss, Perez-Diaz and Gal (2014:123-135), it has been suggested that children with neurodevelopmental disorders often show specific talents in areas such as problem-solving and digital skills. One of the participants also recognised the physical progression of her child, who can crawl and help with being lifted. Research by Bailey, Sahl and Becker (2021:712-728) found that as parents acknowledge their children's skills, this enhances self-esteem and motivation in both the parent and child, creating a positive developmental environment.

Through the lens of the ecological perspective, direct interaction with the environment (microsystem) (Bronfenbrenner, 1992:191-195) could have fostered the development of strengths such as technology skills. Consequently, access to technology involves indirect environmental influences (exosystem) which could be influenced by societal shifts in technological accessibility (Bronfenbrenner, 1992:191-195).

4.3.6.2 Sub-theme 6.2: Increased awareness and understanding

This sub-theme captured how participants developed an increased awareness and deeper understanding of ID-related challenges, leading to personal growth.

> ***P(d):*** *"I think after I've realised that I have a child with autism, or yeah, I have a child with autism. I think, personally, I don't know if this is personal growth, but I am at a point where I want to learn more about such diseases."*
>
> ***P(e)****: "Yeah, there are a few things that I have grown, because most of the time now I understand what their needs are, so that's why I say sometimes don't stress about a lot of things, it's part of growing"*
>
> ***P(b):*** *"Yoh, I'm trying, I'm trying to be in their shoes, I'm trying a lot cause I can …at first, I couldn't look at a child who is disabled or who can't speak, you see, I couldn't, but now I can, yeah. I can even take care of them."*

> ***P(c):*** *"Yeah, for me it did help me a lot. Now that I can say hi, I can face the world with it."*
>
> ***P(a):*** *"I don't know if it wasn't for him, if he wasn't in my life, I have patience, I am a lovable person, and I only seek good for other people, that's my thing."*

A participant expressed an interest in learning more about types of ID, compared to another participant who now understood what ID-related needs are. Most participants experienced increased empathy and patience as they parent their children with IDs. This aligns with findings that caregiving fosters emotional growth, resilience, and compassion (Taylor, Wright, Pothier, Hill & Rosenberg, 2019:161-163). Another participant highlighted a re-evaluation of their values (King, Williams & Roberts, 2022:54-68) with increased emotional intelligence.

Through the lens of the ecological perspective, the mesosystem involves the relationship between different parts of the environment, such as home, school, support systems, etc. (Bronfenbrenner, 1992:191-195). When participants mentioned learning about ID-related challenges and children's strengths suggests that participants were engaged with external resources like healthcare providers. This overlaps with the indirect influences (mesosystem), such as medical professionals or therapy sessions.
Participants described their growth over time, becoming more patient, understanding better, and embracing challenges. This speaks to the chronosystem, which includes the element of time (Bronfenbrenner, 1992:191-195).
This theme discussed that, regardless of known ID-related challenges and stresses, parents also experience positive growth, including increasing awareness and understanding (sub-theme 6.2). Participants acknowledged taking pride in their children's unique abilities, which can enhance both the child's and parent's self-esteem and motivation (Grynszpan et al., 2014; Bailey et al., 2021). These strengths are influenced by the exosystem (technological accessibility) (Bronfenbrenner, 1992). The following section will take a closer look at theme 7.

4.3.7 Theme 7: Suggestions and recommendations

The final theme that emerged from the participant interviews focuses on ID-related suggestions and recommendations. This theme was drawn from the participants' discussion about future proposals and advice to support parents and others caring for children with IDs. The sub-themes that emerged from this theme were the need for community support, promoting awareness and a positive attitude toward intellectual disabilities**,** and improving access to resources and services.

4.3.7.1 Sub-theme 7.1: The need for community support

The following sub-theme focuses on the need for community support as reported by participants from the discussions on suggesting or recommending community support that other individuals in similar situations could benefit from in the future.

> **P(e)**: “*I don't think financial it will help, maybe they can talk to him to say you must respect your mother and your father and you must try to control your temper although we know it's not easy and then talk to him because he likes to talk a lot of things, just show him love and talk to him that's all that I can say to the community”*
>
> ***P(b): “****They can try to support children like that or people living with disability, not to discriminate against them, tease them, if they are kids, cause our kids end up playing alone and not with other kids.*
>
> ***P(a):*** *“Like to be there for him, it doesn’t have to be about money, but just show your face, and we see what you are going through, here is the help, when is your next appointment, we can take you to the hospital or something like that.”*

The responses from participants highlighted the need for community involvement and emotional support to assist them as they face ID-related challenges. Participants collectively emphasised that financial aid is not the primary form of support they seek, but community encouragement and engagement are vital. One participant suggested hands-on support, such as help with accompanying them to hospitals, which aligns with instrumental social support that often improves mental health outcomes (Cohen & Wills, 1985; Thoits, 2011). Another participant recommended emotional support from the community as she struggled with the behavioural challenges following caring for a child with ID, as discussed in sub-theme 4.1. There was also a recommendation to the community on the issue of promoting inclusion and reducing discrimination because the participant’s child negatively impacts the child’s social skills when teased and discriminated against. This aligns with the social inclusion theory, which argues that exclusion impacts a child's self-esteem, emotional development, and social skills (Guralnick, 1999; Lindsay, 2011).

From an ecological perspective, the participants' experiences highlight that an individual’s immediate environment (microsystem) may not always provide sufficient support to address challenges, particularly those related to emotional, behavioural, and social difficulties. Instead, from a larger scale, community involvement, including emotional, social, and practical support from the mesosystem, exosystem, and macrosystem, is essential in fostering resilience and inclusion (Kilanowski, 2017:295; Mbedzi, 2019:95-97).

South African legal frameworks reinforce the importance of community-based support and social inclusion. Section 6(2)(d) of the Children’s Act 38 of 2005 promotes social inclusion and non-discrimination, ensuring that children, particularly those with vulnerabilities, are treated with dignity and respect within their communities.

Moreover, the White Paper on the Rights of Persons with Disabilities (2015) advocates for equal participation and non-discrimination of individuals with disabilities, resonating with the concerns about children with disabilities being excluded from peer interactions. This policy highlights the community’s responsibility to foster inclusive environments that allow for meaningful social interactions and emotional well-being.

4.3.7.2 Sub-theme 7.2: Promoting awareness and a positive attitude toward intellectual disabilities

The following sub-theme focuses on promoting awareness and positive attitudes surrounding IDs. This sub-theme was derived from participants' responses, in which they recommended awareness in the form of educating and promoting positive attitudes around individuals with IDs.

> ***P(b):*** *“…maybe if their parents can teach them that even a child like this, with disability they can still be a normal person.”*
>
> ***P(c):*** *“Like most of the other people, they look at the children like it's a disease, something like that. So, if they can stop being like that, they are also human.”*

> **P(d):** *"I wish in schools or at the clinics or the hospitals, or there'll be maybe nurses that go around, and also there'd be like TV shows where they explain such things. You understand. There must be like an awareness, right. Like at clinics, they must drive an awareness of such diseases. Also, there must be TV shows that drives awareness of such things. In hospitals, they must teach, also in schools, they must teach kids about such things, understand? So that when they grow up, they grow up understanding that, you know, in the world, people are different and such people are treated this way, others are treated that way.*
>
> *Also, in the clinics, when they talk, they must talk about such diseases so that mothers can also understand. Because I feel like there are also a lot of mothers that have kids like this, but they do not know. Some of them, they think that their kids are crazy. Some of them, they think that, yeah, their kids are crazy because they don't have knowledge of what's happening with their kid. So I feel like when they, when we have more awareness and education of such, maybe, yeah, people will understand, understand? Rather than people judging, they will have knowledge of how they can help"*

The participants suggested that education and changing societal perceptions are important and needed to address stigma and discrimination, emphasising that the awareness should begin at home. As discussed in sub-theme 2.1, individuals with IDs experience discrimination due to a lack of understanding (Werner & Scior, 2016). Another participant saw the need within health facilities such as clinics, the media, and schools to raise awareness about IDs.

Using the ecological systems theory, participants suggested that from the immediate environment (microsystem), parents should teach their children about disability to reduce stigma. Another participant addressed it from a macro level, where broader societal attitudes influence how individuals with IDs are perceived and treated. Thus, viewing children with IDs as a "disease" or "crazy" reflects a cultural misconception that needs to be challenged through awareness campaigns (Ali et al., 2012: 2122-2140). For example, the White Paper on the Rights of Persons with Disabilities, pillar 4, calls for promotions and support to empower all persons with disabilities (RSA, Ministry for the Department of Social Development, 2016).

4.3.7.3 Sub-theme 7.3: Improving access to resources and services

The following sub-theme focuses on the suggestion/recommendation to improve access to resources and services as reported by a participant.

> ***P(a):*** *"The only problem with the hospital is when we have to get medication then you'll wait for like 3 hours and is in that condition, he gets frustrated very quickly and they do anything they will say there is a priority, where they will get a file for people who are in wheelchair but still you wait for 3 hours so I don't see the point of the priority…. Yes, they have a system, they prioritise but I don't see the purpose of it working because it's still the same. Yes, even I was there last week, I file in at half past 11 to 2 department. We went to the neurologist, went to the dietician. We were finished at both departments around past 11 and we only got called to get his medication at 3 o'clock to fetch his medication."*
>
> ***P(d):*** *"The challenges are, oh, you see free things. Free things, they just take time… So yeah, I feel like, you know, when it comes to free things, government things, it's very, you don't have access to everything. It's very hard to access things."*

One participant firmly stated the frustration that comes with prolonged hospital visits, where waiting times remain excessively long despite priority systems being in place. Moreover, the delays in receiving medication mirror a global concern about accessibility and healthcare services efficiency for people with disabilities (Krahn, Walker & Correa-De-Araujo, 2015:198-206). A study by Perry, Felce, Kerr, and Bartley (2014:314-326) suggests that inefficiency in service delivery, such as long waiting times, increases stress for individuals with disabilities and their caregivers, thus making healthcare access a barrier rather than a support system. Hence, another participant stated that government resources, "free things", take time to access.

From an exosystem level through the lens of the ecological perspective, government policies and funding allocations could affect the availability of healthcare resources, and the medication distribution process. Thus, there is a need for advocacy for policy changes to improve disability-friendly healthcare systems, as Section 11(d) of the Children's Act 38 of 2005 states that each child living with ID, together with their caregivers, has the right to access necessary support services. This theme highlighted that support is needed from larger outer systems and not only from a micro level so that parents can cope and deal with ID-related challenges (Bronfenbrenner, 1992:191-195; Perron, 2017:198-200).

This final theme highlights the suggestions and recommendations from the participants to support parents of children with IDs. The sub-themes include the need for community support (sub-theme 7.1), promoting awareness and a positive attitude toward IDs (sub-theme 7.2), and improving access to resources and services (sub-theme 7.3). From the ecosystem perspective, these suggestions and recommendations showcase that support is needed from broader systems to help parents caring for children with IDs to cope and deal with ID-related challenges and stressors (Bronfenbrenner, 1992:191-195; Perron, 2017:198-200).

4.4. SUMMARY

This chapter discussed and provided an overview of the study's empirical findings, from the participants' biographical details and their identified themes. The biographical information of the participants included their age, gender, educational levels, occupation, housing, and family composition (number of their children with intellectual disabilities. The empirical findings were discussed under the different themes and sub-themes that emerged from the data analysis and substantiated with data from the literature review. As indicated in section 4.3 above, the main themes are included.

The next chapter presents the conclusion and recommendations for the study.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Chapter five presents a summary of the conclusions and recommendations derived from the study. It begins with an overview of the research, highlighting the extent to which the study’s goal, objectives, and research question have been achieved. Next, it outlines the key findings, conclusions, and recommendations concerning the research methodology, theoretical framework, literature review, participant demographics, and identified themes. Suggestions for future research are discussed, followed by acknowledging the study's limitations. The chapter concludes with final remarks on the overall research.

5.2 SUMMARY

This section summarises the research goal, objectives, and research question, including the extent to which each was met.

5.2.1 Research goal

The goal of the study was to explore the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust. The goal was achieved by meeting clear objectives, a well-defined methodology, an established theoretical framework, and an in-depth review of existing literature.

5.2.2 Objectives of the study

These are the study's objectives and are discussed in terms of how they were met in this study.

5.2.2.1 Objective 1: To explore the psychosocial factors that contribute to the mental health of parents caring for children with intellectual disabilities.

The study successfully explored the psychosocial factors that contribute to the mental health of parents caring for children with IDs. Through participant responses, financial strain and stigma emerged as the most significant stressors affecting parents' well-being. These findings align with existing literature, which highlights the economic and social burdens placed on families caring for children with disabilities.

All participants consistently mentioned financial strain as a primary factor contributing to their distress. The costs associated with specialised diets, diapers, and transportation to healthcare facilities placed an immense burden on families, particularly considering that, from the biographical details, parents only received one income in their households, and others were unemployed. The financial stress affected their emotional well-being and strained family dynamics.

In addition to financial difficulties, stigma significantly influenced parents' mental health. Participants reported experiencing social isolation, negative societal attitudes, and discrimination, which affected their sense of self-worth and emotional resilience. Many parents noted that their communities lacked awareness and understanding of IDs, leading to judgment and exclusion. This societal stigma not only impacted their mental well-being but also discouraged them from seeking support, further deepening their emotional distress. The stigma extended beyond social interactions and influenced access to services, as some parents feared being judged when seeking professional help.

The study findings were further analysed through the ecosystem perspective, which provided a comprehensive understanding of how different levels of social structures influenced parental mental health. At the microsystem level, immediate family relationships were strained due to financial pressures and emotional exhaustion. Some parents found support within their families. At the mesosystem level, the Eersterust Care and Training Centre played a crucial role in supporting the parents, thus alleviating stress. The exosystem level, which includes broader community influences, reinforced the role of stigma. Limited community awareness and unsupportive social environments further contributed to parental distress. Finally, societal attitudes shaped parents' overall experiences at the macrosystem level.

Overall, the study effectively explored the psychosocial factors affecting the mental health of parents caring for children with IDs. The findings highlight the urgent need for financial support programs, community education to reduce stigma, and strengthened support systems at all ecosystem levels. Addressing these factors holistically can improve parental mental health and the overall well-being of children with IDs.

5.2.2.2 Objective 2: To identify the coping strategies that parents use to manage the stress associated with caring for their children.

The study successfully identified the coping strategies that parents use to manage the stress associated with caring for children with IDs. Among the participants, reliance on faith and prayer emerged as the most widely used coping mechanism, followed by family support and coping through distractions like shopping and emotional control. These strategies reflect how parents navigate their daily challenges and attempt to maintain their emotional well-being despite significant stressors, particularly financial strain and stigma.

Faith and prayer played a central role in helping parents manage their stress. Many participants expressed that their religious beliefs gave them strength, hope, and a sense of purpose in their caregiving journey. Prayer was described as a source of comfort, helping parents feel emotionally grounded and reassured despite their hardships. Faith-based communities also played a supportive role by offering encouragement and fostering a sense of belonging, but with a lack of material assistance. The ecosystem perspective highlights the importance of this coping mechanism at the mesosystem level, where religious institutions serve as external sources of emotional and social support.

Family support was another crucial coping strategy, although its availability varied among participants. Parents with understanding and supportive family members reported feeling less isolated and more emotionally resilient. Some relied on extended family for practical assistance, such as childcare, while others leaned on their spouses or close relatives for emotional reassurance. However, not all parents had strong family support systems, as some faced judgment or a lack of understanding about their child’s condition, which, in turn, exacerbated their stress. The effectiveness of family support was thus dependent on the quality of these relationships, reinforcing the importance of strong microsystem connections in parental well-being.

Beyond faith and family, coping through distractions emerged as a notable strategy. Some parents engaged in activities such as shopping to escape their daily struggles momentarily. While these distractions provided temporary relief, they did not necessarily address the root causes of stress. Some participants also practised emotional control, choosing to suppress or downplay their emotions to maintain stability in their households. This form of coping was prevalent among parents who lacked strong external support systems, as they felt the need to remain strong for their children.

In conclusion, the study effectively identified parents' coping strategies to manage stress, with faith and prayer, family support, and dealing with distractions being the most common. While these strategies provided emotional relief, some, such as emotional suppression and avoidance, may require further intervention to prevent long-term psychological strain.

5.2.2.3 Objective 3: To understand the sources of social support that parents receive and how it impacts their mental health.

The study successfully explored the sources of social support that parents of children with IDs receive and how these sources impact their mental health. The findings revealed that family members, the Eersterust Care and Training Centre, and social media were participants' primary sources of support. However, the effectiveness of these support systems varied, influencing the stress and emotional well-being experienced by parents. Those with consistent and reliable support reported feeling less isolated and more emotionally resilient, while those with limited support networks faced more significant challenges in coping with caregiving demands.

Family members played a crucial role in shaping the mental health of parents, although the level of support differed. Some parents had understanding and involved relatives who assisted with caregiving responsibilities or provided emotional reassurance. These parents reported experiencing less stress and better emotional stability, as they did not feel alone in managing the daily demands of caregiving. However, other parents faced a lack of support or judgment from family members, which intensified their emotional burden. This highlights the importance of microsystem influences, where the quality of close relationships directly affects the mental well-being of parents.

The Eersterust Care and Training Centre was another key source of support for some participants. This centre provided specialised care, educational resources, and structured programs for children with IDs, which helped alleviate some of the stress experienced by parents. The centres' services benefited children and provided parents with a sense of relief, guidance, and a supportive network of professionals and other caregivers. From an ecosystem perspective, this support operated at the mesosystem level, as parents engaged with external institutions that directly influenced their caregiving experience. Additionally, social media emerged as an unexpected yet significant source of support. Some parents relied on online communities and social media platforms to learn about IDs, share experiences, and seek advice. This form of digital support allowed parents to connect with others facing similar challenges, reducing feelings of isolation. Social media also served as an educational tool, helping parents better understand their child's condition and explore coping strategies. From an ecosystem perspective, this reflects the exosystem level, where indirect influences, such as technology and information accessibility, impact parental mental health.

While these sources of support provided relief for some parents, the study also revealed gaps in formal support systems. Many participants expressed the need for more structured government assistance, accessible financial aid, and inclusive community programs to reduce caregiving stress further. In conclusion, the study effectively identified family members, the Eersterust Care and Training Centre, and social media as parents' primary sources of social support. While these sources helped parents cope with caregiving challenges, their impact depended on the level of accessibility, family dynamics, and external resources available. The findings highlight the need for enhanced formal support structures, increased awareness of available resources, and strengthened community-based initiatives to improve parental mental health and overall caregiving experiences.

5.2.3 Research question

The research question in the conducted study was:

"What is the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust?"

This research question was addressed by conducting exploratory semi-structured interviews with parents caring for children with IDs in Eersterust. The interviews were one-on-one with five participants who met the inclusion criteria. Data was collected using the RTA, and seven themes and 17 sub-themes were generated, which are briefly discussed in section 4.3. These themes and sub-themes aided in answering the research question as various psychosocial factors influencing the mental health of parents caring for children with IDs were explored. The ecosystem perspective also helped the researcher understand the different psychosocial factors arising from participants' microsystems, mesosystems, exosystem, macrosystem, and chronosystems and their impact on participants at both individual and broader societal levels.

5.3 KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

The following section provides an in-depth examination of the study's key findings, conclusions, and recommendations. It begins with conclusions from the research methodology, theoretical framework, and literature review. Then, it addresses conclusions and recommendations related to participants' biographical details. Finally, it presents key findings, conclusions, and recommendations based on the thematic analysis.

5.3.1 Conclusions from the Research Methodology

The researcher employed qualitative research methods to investigate and gain a deeper understanding of the psychosocial factors impacting the mental health of parents caring for children with intellectual disabilities (IDs). This approach allowed the researcher to collect data in an environment where participants felt comfortable sharing their experiences. The study followed an instrumental single case study design, which was well-suited for exploring the specific issue of psychosocial factors influencing the mental health of these parents. This design helped the researcher maintain focus, aligning effectively with the study's exploratory aim and interpretivist paradigm.

The research was classified as applied research, as it sought to provide practical insights into the challenges faced by parents caring for children with IDs. The findings are expected to support social workers, healthcare providers, policymakers, and other relevant stakeholders in better understanding the psychosocial factors affecting these parents' mental health. Participants were selected using purposive sampling based on criteria such as being a parent of a child with an ID living in Eersterust, with assistance from a gatekeeper at the Eersterust Training Centre. The study's sample size (five participants) was determined through the concept of information power, considering the study's narrow focus, its qualitative nature, the use of an ecological perspective, and the application of the RTA method for data analysis, all of which contributed to gathering rich and meaningful data.

The researcher conducted semi-structured one-on-one interviews guided by an interview schedule to collect data. This method allowed for a balance between flexibility and structure, fostering engaging conversations with participants and ensuring valuable data collection. A pilot study was carried out before the primary interviews, making minor adjustments to the interview guide. All interviews were audio-recorded and transcribed for analysis using RTA. The transcripts were analysed, and relevant codes from participants' responses were identified separately; then, all similar codes from each participant were compiled into Microsoft Word and Excel documents for more straightforward discussion and analysis. These codes were then used to identify themes and sub-themes, which were compiled into the final codes and transferred into the Word document under the appropriate themes and sub-themes. To ensure data quality, strategies such as peer debriefing, thick descriptions, audit trails, and reflexivity were employed, ensuring the trustworthiness of the data through credibility, transferability, dependability, and confirmability.

Ethical considerations were adhered to throughout the research process. In conclusion, the research design, methodology, and methods of data collection, analysis, and ethical management were appropriate and successful in achieving the study's objectives.

5.3.2 Conclusions from the theoretical framework and literature review

The study was grounded in the ecosystem perspective, which provided a comprehensive lens for understanding the various interconnected factors influencing the mental health of parents caring for children with IDs. By examining the interplay between micro-, meso-, exo, and macro-level systems, the study highlighted how individual, family, community, and societal influences shape parental experiences. The findings reinforced the relevance of this framework in social work by demonstrating that parental mental health is not solely an individual struggle but a product of broader systemic interactions. The study underscores the need for holistic interventions that address the psychological well-being of parents and their access to social support, healthcare services, and community resources. Future research should continue using the ecosystem perspective to explore additional systemic factors, such as policy implications and workplace support, in mitigating parental stress.

The literature review demonstrated that parents of children with intellectual disabilities faced significant psychosocial challenges, including emotional distress, financial strain, and social isolation. Studies highlighted that these challenges often led to increased stress, anxiety, and depression among caregivers, impacting their overall well-being. Additionally, research emphasised the importance of social support, coping strategies, and resource access in mitigating these difficulties. The findings suggested that a holistic approach incorporating mental health interventions, financial assistance, and inclusive policies was necessary to enhance the well-being of caregivers.

5.3.3 Conclusions on the biographical details

All participants are parents caring for children with IDs and residing in Eersterust, which made them suitable and relevant participants to study the influence of psychosocial factors on the mental health of parents caring for children with IDs in Eersterust.

The study also reinforces the global and national trend of women being the primary caregivers for children with disabilities, as all participants were female. This gendered burden stems from traditional cultural norms and societal expectations, which may contribute to heightened emotional distress, financial strain, and social isolation among female caregivers. Participants' educational backgrounds ranged from Grade 10 to tertiary education, reflecting disparities in access to quality education in South Africa. Lower educational attainment may hinder a parent's ability to access information, navigate support systems, and advocate effectively for their child's needs, potentially increasing stress levels.

Regarding employment, most participants were employed at the Eersterust Care and Training Centre, while one worked at another company, and only one participant was unemployed. This finding highlights the significant role that specialised institutions play in providing job opportunities within the disability sector. Employment within such institutions may also offer caregivers increased awareness and understanding of intellectual disabilities. However, parents working outside specialised care settings may face more significant work-life conflict, especially in workplaces that lack family-friendly policies. Housing conditions among participants ranged from three- to four-bedroomed homes, indicating a relatively stable socioeconomic status. Adequate housing is essential in providing a safe and structured environment for both caregivers and children with disabilities. Stable housing reduces stressors such as overcrowding, which can negatively impact family dynamics and overall well-being.

In terms of family composition, the study revealed that of participants had one child, another had two children, and had three children, with a mean of 1.8 children per participant. The number of children in a household directly impacts caregiving responsibilities at the microsystem level. These biographical insights highlight the multifaceted challenges faced by parents of children with intellectual disabilities within the South African context.

5.3.4 Key findings, conclusions, and recommendations on the thematic analysis

The following section presents the main findings, conclusions, and recommendations related to the themes that emerged from the study. A detailed list of all the themes and sub-themes identified during the data analysis can be found in Table 4.3.

5.3.4.1 Theme 1: Emotional and psychological impact

The first theme focused on the emotional and psychological impact experienced by participants as they cared for their children with IDs.

5.3.4.1.1 Key findings

Concerning the emotional and psychological impact of parenting children with IDs, participants initially experienced denial and difficulty in accepting their child’s ID. Some participants went through a fluctuation of acknowledging and regressing, which was also influenced by societal and familial expectations. Participants also expressed deep concern over their child’s ability to function independently. Many worried about their child’s well-being after their passing. Furthermore, participants reported emotional exhaustion and burnout, where caring for their children with IDs led to stress, anxiety, and depression. The emotional distress spilt over into other areas of their lives, affecting relationships and social interactions.

From an ecosystem perspective, societal (macrosystem) stigma and misconceptions about intellectual disabilities reinforced denial and delayed acceptance. Cultural expectations about parenting and caregiving further influenced emotional distress.

5.3.4.1.2 Conclusions

From the participants’ findings, it may be concluded that parenting a child with ID presented significant emotional and psychological challenges influenced by personal, familial, and societal factors. Thus, the broader societal and cultural environment affected participants' acceptance of their child’s condition, stress levels, and concerns about their child’s long-term independence. Moreover, the lack of structured support systems exacerbated their fear, burnout, and uncertainty about the future.

5.3.4.1.3 Recommendations

- ✓ Participants struggled with accepting their children’s diagnosis of ID. Therefore, participants can benefit from educational workshops in hospitals and clinics to help them navigate the stages of acceptance and develop coping strategies.
- ✓ Social workers could also implement psycho-social support programs for parents of children with IDs, such as peer support groups, to help them with their emotional well-being.
- ✓ As most participants are fearful about their child’s future, social workers could connect families with legal processes or relevant resources, such as long-term care planning services, to assist parents in preparing for their child’s future after their passing.

5.3.4.2 Theme 2: Social challenges and exclusion

This theme focused on the social challenges and exclusion experienced by participants as parents of children living with IDs.

5.3.4.2.1 Key findings

The study revealed significant social challenges faced by parents caring for children with intellectual disabilities (IDs), particularly stigma and judgment, avoidance of social settings, and lack of community awareness. Participants reported experiencing public stigma, such as name-calling, judgmental stares, and societal expectations for their children to "act normal." These experiences led to emotional distress and, in some cases, self-stigma, where parents internalised societal prejudices. Many participants expressed difficulties forming romantic relationships because they feared potential partners would not accept their child with an ID. Additionally, some parents preferred staying close to their children rather than exposing themselves to societal judgment.

Avoiding social settings was another key challenge, as parents often withdrew from public spaces like malls and social gatherings due to fear of judgment, questioning, and embarrassment. This self-imposed isolation limited their access to supportive networks, negatively impacting their well-being. Some participants also noted that being sole caregivers made it challenging to engage in social activities, reinforcing their exclusion.

Lack of awareness about IDs within the community was a recurring concern. Participants shared that friends, family members, and society at large often misunderstood their children's disabilities, assuming they were "fine" based on their physical appearance. The absence of knowledge about IDs contributed to stigmatisation and unsupportive attitudes, further isolating these parents and their children. The findings highlighted the need for disability education and awareness programs to promote understanding and inclusivity.

5.3.4.2.2 Conclusions

The study demonstrated that parents caring for children with IDs face substantial social exclusion due to stigma, isolation, and a general lack of community awareness. These challenges affect their emotional well-being, social interactions, and access to supportive networks. The ecological systems perspective suggests that stigma and exclusion occur at multiple levels, including societal norms (macrosystem), family and social structures (mesosystem), and individual experiences (microsystem). Without targeted interventions, these parents will continue to face barriers in their social and emotional lives.

5.3.4.2.3 Recommendations

- ✓ Multi-disciplinary collaboration teams, such as social workers, nurses, and community leaders, work together and implement educational initiatives to increase awareness and understanding of intellectual disabilities within communities, schools, workplaces, and even in the media (representation). This can help reduce stigma and promote inclusivity.
- ✓ Considering the presence of organisations such as Eersterust Care and Training Centre that serve people with disabilities and their families, it can be recommended that more inclusive public spaces/institutions be supported and established where children with IDs and their families are accommodated.

5.3.4.3 Theme 3: Financial strain

The third theme focused on the financial strain participants experienced as parents of children living with IDs.

5.3.4.3.1 Key findings

The study highlights the severe financial strain experienced by parents caring for children with intellectual disabilities (IDs). The primary financial burden is the high costs of essential items such as diapers, specialised diets, and feeding aids. Many participants expressed difficulty affording these necessities, particularly single parents, those unemployed, or those dependent on a single income. The financial strain was exacerbated by the increasing out-of-pocket expenses required for children with special healthcare needs. This financial burden influences household budgeting, further increasing caregivers' stress. Bronfenbrenner’s ecosystem model shows that economic constraints at both the micro (household) and macro (societal) levels impact parental well-being and their ability to provide adequate care for their children.

5.3.4.3.2 Conclusions

The financial strain faced by caregivers of children with IDs is a significant stressor, negatively affecting their mental and emotional well-being. The high cost of specialised care contributes to increased caregiver burden, particularly for those with limited financial support. The economic challenges associated with raising a child with an intellectual disability are not only personal but also systemic, requiring broader intervention at the community and policy levels. The financial impact of caregiving further influences the overall stress levels of parents, highlighting the need for targeted support mechanisms.

5.3.4.3.3 Recommendations

- ✓ Social workers can assist caregivers in applying for disability grants, child support grants, and medical aid benefits. They can guide navigating government and non-governmental financial support systems and advocate for policies that improve access to these funds.

5.3.4.4 Theme 4: Parenting challenges

Parenting challenges were the fourth theme identified that participants experienced as parents of children with IDs.

5.3.4.4.1 Key findings

Parents caring for children with intellectual disabilities (IDs) face significant behavioural challenges, particularly aggression, disobedience, and difficulties with social and emotional expression. One parent reported being physically attacked by her child, experiencing verbal insults, and struggling with disobedience, which left her feeling helpless and distressed. Some children also exhibited a lack of emotional responsiveness, such as not reacting to the loss of a loved one or unexpectedly shouting in public, which led to social stigma and judgment from others. These behavioural difficulties align with existing research, which highlights the prevalence of aggression, social withdrawal, and emotional struggles in children with IDs.

The impact of these challenges on parents was profound, with many expressing feelings of emotional exhaustion, fear, and self-doubt regarding their parenting abilities. Some parents blamed themselves for their child's condition or questioned whether their parenting styles were contributing to their child's behaviour. The constant struggle to manage aggressive outbursts and emotional detachment placed immense strain on their mental well-being, affecting their confidence as caregivers and their overall quality of life.

In addition to behavioural challenges, cultural and traditional beliefs significantly shaped parents' caregiving experiences. Some caregivers reported being pressured by family members to participate in traditional rituals, such as naming ceremonies or cultural cleansing, in an attempt to "cure" their child's condition. Others held faith-based beliefs, viewing their child's condition as a divine blessing rather than a medical issue. The influence of cultural and religious beliefs highlights the complexity of caregiving, where parents must navigate the expectations of their families and communities while also considering the best medical and psychological care for their children.

An ecological perspective further illustrates how these challenges operate across multiple levels. Parents experience direct stress from their child's behaviour at the microsystem level. Family expectations and societal norms support or hinder their caregiving journey at the mesosystem and macrosystem levels. Finally, religious and cultural beliefs can limit access to necessary medical and psychological interventions at the exosystem level. The intersection of these factors creates a caregiving experience that is emotionally, socially, and mentally demanding for parents.

5.3.4.4.2 Conclusions

The findings highlight that parents of children with IDs face unique and complex challenges that affect their emotional and mental well-being. Behavioural difficulties, particularly aggression, and disobedience, contribute to high levels of stress and feelings of helplessness among caregivers. Cultural and religious beliefs further shape caregiving experiences, sometimes acting as barriers to professional support. The ecological model demonstrates that multiple levels of influence—family, community, societal expectations, and institutions—either support or complicate the parenting journey. Without appropriate support structures, caregivers risk experiencing significant emotional distress, which may impact their ability to provide adequate care for their children.

5.3.4.4.3 Recommendations

- ✓ Social workers can play a crucial role in supporting parents by providing education, emotional support, crisis intervention, and community advocacy. One essential area of intervention is **parental training and behavioural management support.** Social workers can design and facilitate workshops to equip parents with practical strategies for managing aggression, disobedience, and emotional regulation challenges. Parenting support groups can also offer a safe space for caregivers to share their experiences, seek advice, and receive guidance from professionals trained in handling children with IDs. Connecting parents with psychologists or therapists specialising in child behaviour management can also provide them with evidence-based interventions tailored to their child's needs.

- ✓ Cultural and faith-based sensitisation should be another focus area. Social workers can **engage with traditional and religious leaders** to foster dialogue about the intersection of faith, culture, and medical interventions. Creating **culturally sensitive information materials** that educate families on the realities of intellectual disabilities while respecting their beliefs can help bridge the gap between traditional practices and evidence-based medical care. Encouraging caregivers to see medical interventions as complementary rather than contradictory to their faith can promote a more balanced approach to caregiving.

5.3.4.5 Theme 5: Coping Mechanisms

The fifth theme focused on the coping mechanisms that participants used to deal with ID-related challenges and stressors.

5.3.4.5.1 Key findings

The findings of this study highlight the various coping mechanisms employed by parents raising children with intellectual disabilities. Faith and prayer emerged as significant sources of psychological resilience, providing participants with emotional strength to navigate their challenges. However, while spirituality was a key coping strategy, some participants expressed feelings of inadequate support from their religious communities, indicating that faith alone may not always be sufficient without tangible assistance. Family support was identified as a crucial protective factor, with participants emphasising the emotional and practical relief provided by spouses, partners, and extended family members. Notably, some participants were surprised by the level of understanding and support they received, particularly from their parents, which contributed positively to their coping experience. Conversely, the absence of family support was recognised as a potential risk factor for burnout, stress, and emotional distress.

In addition to spiritual and familial support, participants also adopted emotion-focused coping strategies such as shopping, engaging in leisure activities, and suppressing emotions to manage stress. While these methods provided temporary relief, unresolved emotional stress remained a concern, highlighting the need for more sustainable coping mechanisms. From an ecological perspective, the findings suggest that coping mechanisms operate primarily within the microsystem, which includes personal beliefs, close family relationships, and individual behavioural patterns. Additionally, the mesosystem, which consists of connections between family and religious institutions, also shaped participants' coping experiences.

5.3.4.5.2 Conclusions

Ultimately, the study concludes that while personal coping mechanisms such as faith, family support, and distractions are valuable, they must be complemented by a strong external support system to prevent long-term psychological strain. A holistic approach that integrates individual resilience, family support, and broader community involvement is essential in ensuring the well-being of caregivers raising children with intellectual disabilities.

5.3.4.5.3 Recommendations

- ✓ Given the reliance on faith and prayer as coping mechanisms, social workers could engage with religious and community leaders to create more inclusive and supportive environments for these parents. This can include developing faith-based support initiatives, educating religious leaders on intellectual disabilities, and advocating for churches and community organisations to provide practical assistance, such as respite care or financial aid.
- ✓ While some parents rely on distractions and emotional suppression as coping mechanisms, social workers should educate them on healthier alternatives. Psychoeducational programs and self-care workshops can help parents develop effective stress management techniques, such as mindfulness, problem-solving skills, and seeking professional help when necessary

5.3.4.6 Theme 6: Positive aspects and personal growth

The sixth theme focused on the positive aspects and personal growth experienced by parents of children with IDs.

5.3.4.6.1 Key findings

The study highlighted several key findings related to the personal growth and positive experiences of parents raising children with intellectual disabilities (ID). First, participants reported that they were able to celebrate their children’s strengths, with many acknowledging their children's unique abilities in areas such as technology, cooking, and physical development. These strengths enhanced the children's self-esteem and contributed to a positive developmental environment for both the parent and child. Parents found themselves increasingly motivated and proud of these abilities, which aligned with existing research that suggests children with neurodevelopmental disorders may have specific talents that can contribute to their personal growth.

Second, the study found that participants experienced significant personal growth during caregiving. As they learned more about their child’s condition, many parents became more patient, empathetic, and emotionally intelligent. Engagement with external resources, such as healthcare providers and therapy sessions, facilitated this personal growth, which helped parents better understand their child's needs. As a result, many parents reported feeling more equipped to face challenges, recognising the value of patience, understanding, and emotional intelligence in their caregiving role.

5.3.4.6.2 Conclusions

In conclusion, the study underscores the positive aspects of parenting children with intellectual disabilities, highlighting both the strengths that children exhibit and the personal growth that parents experience. While the challenges associated with raising a child with ID are significant, parents also report meaningful growth in terms of emotional intelligence, patience, and empathy. The caregiving process often leads to increased awareness and understanding of the child’s unique abilities, which enhances the parent-child relationship and fosters a more supportive and nurturing environment. This positive development, both for the child and the parent, reflects caregiving's dynamic and evolving nature and its transformative effect on individuals.

5.3.4.6.3 Recommendations

- ✓ It is recommended that more establishments and peer support networks, such as Eersterust Care and Training Centre, be established where parents can share experiences, celebrate their children's strengths, and receive emotional support. Creating a safe space for parents to express their challenges and successes can enhance their resilience and well-being. Social workers can coordinate these groups and offer structured discussions on empowerment and skill-building.

5.3.4.7 Theme 7: Suggestions and Recommendations

The seventh theme focused on the suggestions and recommendations given by the participants in the study.

5.3.4.7.1 Key findings

The findings from this theme reveal that parents of children with intellectual disabilities (IDs) emphasise the need for more incredible community support, increased awareness, and improved access to resources and services. Participants highlighted that emotional and social support from the community is more valuable than financial assistance. They expressed that community members should engage with their children in a caring and inclusive manner rather than isolating or discriminating against them. The importance of inclusion and social acceptance was a recurring concern, with participants noting that discrimination negatively impacts their children's emotional and social development. Additionally, awareness campaigns were recommended to challenge misconceptions about intellectual disabilities. Participants suggested that schools, clinics, and the media should actively educate the public to reduce stigma and foster a more understanding society. Lastly, access to healthcare and essential services remains challenging, with participants reporting long waiting times and inefficiencies in the hospital system. Despite having priority systems in place, delays in receiving medication and accessing specialists cause frustration and stress for both parents and their children.

5.3.4.7.2 Conclusions

In conclusion, these findings highlight the urgent need for multi-level interventions to support parents caring for children with IDs. From an ecological perspective, support should not be limited to the immediate family but should extend to broader systems, including the community, healthcare facilities, and policymakers. The lack of social inclusion and awareness contributes to stigma, while inefficiencies in service delivery increase caregiver burden. Addressing these issues requires a combination of community-driven initiatives, education campaigns, and systemic improvements in healthcare and social services. Strengthening these areas can foster a more inclusive and supportive environment for children with IDs and their families.

5.3.4.7.3 Recommendations

Social workers play a crucial role in bridging the gap between families, communities, and service providers, ensuring holistic support for children with intellectual disabilities and their caregivers. Thus, these are the suggested recommendations:

- ✓ Social workers can facilitate community education programs to promote inclusion, reduce discrimination, and provide emotional support groups for parents caring for children with IDs.
- ✓ Social workers can help families navigate healthcare and social services, advocate for better policies and service delivery, and provide case management to ensure timely access to crucial resources.

5.4 RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the biographical details of participants, the research methodology, the findings, and the ecosystem perspective, here are some potential recommendations for future research studies:

- ✓ The current study focused on parents caring for one child with intellectual disabilities (IDs). Future research can explore how caregiving dynamics, stress levels, coping mechanisms, and support systems differ when parents are responsible for more than one child with an ID.
- ✓ From the biographical details, only female participants participated in this research study. Therefore, future research could explore the specific experiences of fathers caring for children with IDs, including their coping strategies, mental health, and involvement in caregiving.
- ✓ Taking into consideration that some parents have more than one child, future research could explore the experiences of siblings of children with IDs and their perceptions of parental mental health. Understanding family dynamics can provide a more holistic view of the psychosocial impact.

5.5 LIMITATIONS AND CHALLENGES OF THE STUDY

These are various limitations and challenges that the researcher faced during the study:

- ✓ The study did not account for the severity of intellectual disabilities in the child (e.g., mild, moderate, severe); it may overlook the fact that the mental health impact on parents may vary significantly depending on the level of care required.
- ✓ The study only focused on parents caring for one child with intellectual disabilities (IDs). This narrow focus may limit the understanding of the broader experiences of parents, especially those caring for multiple children with IDs, which can lead to different caregiving challenges and stressors.
- ✓ Another limitation is the study's focus solely on female parents. This limits the understanding of how male parents experience caregiving for children with IDs and how their mental health, coping strategies, and involvement differ from female caregivers. Future research could benefit from including male parents to provide a more balanced view of caregiving dynamics in the family context.

5.6 FINAL CONCLUDING REMARKS

This study has highlighted the multifaceted psychosocial challenges faced by parents of children with IDs at Eersterust. The findings emphasise the emotional and psychological toll these parents endure, including struggles with denial and acceptance, fear for their child’s future, and feelings of emotional exhaustion and burnout. These challenges are compounded by social stigma, exclusion, and a lack of awareness in the community, which often exacerbate the sense of isolation experienced by these parents. Financial strain remains a significant concern, particularly related to the costs associated with specialised care and resources, such as diapers and special diets. The study also identifies critical parenting challenges, including managing behavioural difficulties and balancing traditional cultural beliefs with the realities of raising a child with intellectual disabilities.

Despite these adversities, many parents demonstrate remarkable resilience through coping mechanisms such as reliance on faith, family support, and emotional control. Additionally, the strength and progress of their children foster a sense of personal growth and increased awareness. Parents also strongly desire enhanced community support, greater awareness, and improved access to resources and services, which could significantly alleviate their burdens. Ultimately, this study underscores the importance of holistic support systems that address the practical needs of parents and recognise and validate their emotional, social, and psychological experiences. For future intervention strategies, it is crucial to focus on reducing stigma, fostering inclusive communities, and enhancing the availability of resources to ensure that parents and children with IDs can thrive.

REFERENCES

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J. & Wright, M.T. 2019. *Participatory research for health and social well-being.* Cham: Springer.

Adler, E.S. & Clark, R. 2015. *An invitation to social research: how it's done.* 5th ed. Stamford, CT: Cengage Learning.

Adom, D., Yeboah, A. & Ankrah, A.K. 2016. Constructivism philosophical paradigm: Implications for research, teaching and learning. *Global Journal of Arts, Humanities and Social Sciences,* 4(10):1-9.

Alharahsheh, H.H. & Pius, A. 2020. A review of key paradigms: Positivism vs. Interpretivism. *Global Academic Journal of Humanities and Social Sciences*, 2(3):39-43. doi: https://doi.org/10.36348/gajhss.2020.v02i03.001

American Academy of Paediatrics. 2015. *Intellectual Disability*. Retrieved from https://pediatrics.aappublications.org

American Psychiatric Association. 2022. *The diagnostic and statistical manual of mental disorders.* 5th ed., text rev. Washington, D.C.: American Psychiatric Publishing.

American Psychological Association. 2023. *APA Dictionary of Psychology*. https://dictionary.apa.org/

Azeem, M.W., Dogar, I.A., Shah, S., Cheema, M.A., Asmat, A., Akbar, M., Kousar, S. & Haider, I.I. 2013. Anxiety and depression among parents of children with intellectual disability in Pakistan. *Journal of the Canadian Academy of Child and Adolescent Psychiatry,* 22(4):290-296.

Babbie, E. 2017. *The basics of social research*. 7th ed. Boston, MA: Cengage Learning.

Babbie, E. 2021. *The practice of social research.* 15th ed. Boston, MA: Cengage Learning.

Baker, K., Devine, R.T., Ng-Cordell, E., Raymond, F.L., IMAGINE-ID consortium, & Hughes, C. 2021. Childhood intellectual disability and parents' mental health:

integrating social, psychological and genetic influences. *The British Journal of Psychiatry,* 218(1):315-322.

Barlow, D.H., Durand, V.M., Du Plessis, L.M. & Visser, C. 2017. *Abnormal psychology: An integrative approach.* 1st SA ed. Andover, UK: Cengage Learning.

Baumgardner, D. J. 2019. Social Isolation Among Families Caring for Children With Disabilities. *Journal of patient-centred research and reviews*, *6*(4):229–232. https://doi.org/10.17294/2330-0698.1726

Bigby, C. & Frawley, P. 2018. *Social work practice and intellectual disability: Working to support change.* London, UK: Bloomsbury Publishing.

Braun, V. & Clarke, V. 2022. *Thematic analysis: A practical guide.* London, UK: Sage.

Broom, A. 2006. Ethical issues in social research. *Complementary Therapies in Medicine,* 14(2):151-156.

Bronfenbrenner, U. 1986. Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology,* 22(6):723-742.

Bronfenbrenner, U. 1992. *Ecological systems theory.* Philadelphia, PA: Jessica Kingsley.

Burke, M. M., & Heller, T. 2016. Disparities in support for family caregivers of individuals with intellectual and developmental disabilities: A systematic review. Journal of Policy and Practice in Intellectual Disabilities, 13(1), 11-30.

Byrne, D. 2021. A worked example of Braun and Clarke’s approach to reflexive thematic analysis. *Quality & Quantity,* 56(1):1391-1412.

Capri, C., Abrahams, L., McKenzie, J., Mkabile, S., Saptouw, M., Hooper, A., Smith, P., Adnams, C., Swartz, L. & Ockert, O.C. 2018. Intellectual disability rights and inclusive citizenship in South Africa: What can a scoping review tell us?. *African Journal of Disability*, 7(1):1-17. doi: https://doi.org/10520/EJC-e78d97391

Centres for Disease Control and Prevention. 2022. *Developmental Disabilities*. https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html Accessed on: 29/04/2022.

Chauke, T., Poggenpoel, M., Myburgh, C.P.H. & Ntshingila, N. 2021. Experiences of parents of an adolescent with intellectual disability in Giyani, Limpopo province, South Africa. *Health SA Gesondheid,* 26(1):1-9.

Cherry, K. 2023. *Comprehensive Guide to the Bronfenbrenner Ecological Model.* https://www.verywellmind.com/bronfenbrenner-ecological-model-7643403 Accessed on: 16/08/2023.

Children's Act 38 of 2005. (Published in the *Government Gazette*, (28944). Pretoria: Government Printer).

Christensen, L.B., Burke, R.J. & Turner, L.A. 2015. *Research Methods, Design, and Analysis.* 12th ed. England: Pearson.

Cithambaram, K., Corby, D. & Rajendran, S.S. 2024. Experiences of family carers in providing care to children with intellectual disabilities in India: A qualitative evidence synthesis. *Journal of Applied Research in Intellectual Disabilities,* 37(5):1-15.

Coady, N. & Lehmann, P. 2008. *Theoretical Perspectives for Direct Social Work Practice. A Generalist-Eclectic Approach.* 2nd ed. NY: Springer.

Compas, B. E., Jaser, S. S., Dunbar, J. P., Watson, K. H., Bettis, A. H., Gruhn, M. A. & Williams, E. K. 2014. Coping and Emotion Regulation from Childhood to Early Adulthood: Points of Convergence and Divergence. *Australian journal of psychology*, 66(2):71–81.

Currie, G. & Szabo, J. 2020. Social isolation and exclusion: the parents' experience of caring for children with rare neurodevelopmental disorders. *International Journal of Qualitative Studies on Health and Well-being,* 15(1):1-10.

Department of Education. 2001. Education White Paper 6: Special Needs Education – Building an Inclusive Education and Training System.

Department of Social Development. 2015. White Paper on the Rights of Persons with Disabilities (WPRPD).

Disability Info South Africa. 2024. *Care Centres & Homes of Safety.* http://disabilityinfosa.co.za/intellectual-impairments/care-centres-homes-of-safety/

Eerterust. 2025. Available at: https://af.wikipedia.org/wiki/Eersterust

Emerson, E., & Hatton, C. 2007. Mental health of children and adolescents with intellectual disabilities in Britain. *The British journal of psychiatry: the journal of mental science*, 191(1):493–499.

Employment Equity Act 1998. (Published in the *Government Gazette*, (19370). Pretoria: Government Printer).

Eriksson, M., Ghazinour, M. & Hammarstrom, A. 2018. Different uses of Bronfenbrenner's ecological theory in public mental health research: what is their value for guiding public mental health policy and practice? *Social Theory Health,* 16(4):414-433.

Evans, O.G. 2023. *Bronfenbrenner's Ecological Systems Theory.* https://www.simplypsychology.org/bronfenbrenner.html?nowprocket=1

Fieggen, K., Lambie, L. & Donald, K. 2019. Investigating developmental delay in South Africa: A pragmatic approach. *South African Medical Journal,* 109(4):210-213.

Foskett, K. 2014. *Intellectual Disability in South Africa.* Pretoria: Includid.

Fouché, C.B. & Geyer, L.S. 2021. Developing a research proposal. In: Fouché, C.B. (Ed.)., Strydom, H. & Roestenburg, W.J.H. *Research at the grassroots: For the social sciences and human service professions.* 5th ed. Pretoria: Van Schaik.

Genereaux, D., Van Karnebeek, C.D. & Birch, P.H. 2015. Costs of caring for children with an intellectual developmental disorder. *Disability Health Journal*, 8(4):646-651.

Geyer, L.S. 2021. Interviews as data collection methods. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (Eds.). *Research at the grassroots: For the social sciences and human services professions*. 5th ed. Pretoria: Van Schaik Publishers.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. 2011. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child: care, health and development*, *37*(2): 175–183.

Grynszpan, O., Weiss, P. L., Perez-Diaz, F. & Gal, E. 2014. Innovative technology-based interventions for autism spectrum disorders: a meta-analysis. *Autism: the international journal of research and practice*, *18*(4):346–361.

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. 2005. How do carers of disabled children cope? The Ugandan perspective." Child: Care, Health and Development, 31(2), 151-160.

Hoyle, J.N., Laditka, J.N & Laditka, S.B. 2021. Mental Health Risks of Parents of Children with Developmental Disabilities: A Nationally Representative Study in the United States. *Disability and Health Journal,* 14(2):1-27.

Islam, M.A., Rahman, A. & Akhtar, S. 2022. Psychosocial impact of parenting children with intellectual disabilities in Bangladesh. *International Journal of Public Health Science,* 11(1):211-219.

Junjie, M. & Yingxin, M. 2022. The discussions of positivism and interpretivism. *Global Academic Journal of Humanities and Social Sciences*, 4(1):10-14. doi: https://doi.org/10.36348/gajhss.2022.v04i01.002

Kamenopoulou, L. 2016. Ecological Systems Theory: A valuable framework for research on inclusion and special educational needs/disabilities. *Global Observatory for Inclusion,* 88(4):515-527.

Kavaliauskiene, J. & Rimkuviene, A. 2017. Social work skills working with mentally disabled persons: case overview. *Konińskie Studia Społeczno-Ekonomiczne,* 3(2):153-159.

Kendall, K. & Owen, M.J., 2015. Intellectual disability and psychiatric comorbidity: Challenges and clinical issues. *Psychiatric Times*, 32(5):60-63. doi: https://doi.org//98860

Kilanowski, J.F. 2017. Breadth of the socio-ecological model. *Journal of Agromedicine,* 22(4):295-297. doi: https://doi.org/210.1080/1059924X.1052017.1358971

King, G., Williams, D. & Roberts, L. 2022. Personal growth and emotional resilience in caregivers of children with disabilities. *Family Relations Journal*, 62(1):54-68.

Knifton, L. & Inglis, G. 2020. Poverty and mental health: policy, practice and research implications. *BJPsych,* 44(1):193-196.

Kütük, M.Ö., Tufan, A.E., Kılıçaslan, F., Güler, G., Çelik, F., Altıntaş, E., Gökçen, C., Karadağ, M., Yektaş, C., Mutluer, T., Kandemir, H., Büber, A.,Topal, Z., Acikbas, U., Giray, A. & Kütük, Ö. 2021. High Depression Symptoms and Burnout Levels Among Parents of Children with Autism Spectrum Disorders: A Multi-Center, Cross-Sectional, Case–Control Study. *Journal of Autism and Developmental Disorders,* 51(1):4086-4099.

Lau, J. & Ng, K. 2014. Conceptualizing the counseling training environment using Bronfenbrenner's ecological theory. *International Journal for the Advancement of Counselling,* 36(1):423-439. doi: https://doi.org/410.1007/s10447-10014-19220-10445

Leedy, P.D. & Ormrod, J.E. 2015. *Practical research: Planning and design.* 11th ed. New York, NY: Pearson.

Leedy, P.D. & Ormrod, J.E. 2019. *Practical research: Planning and design.* 12th ed. New York, NY: Pearson.

Lee, K., Cascella, M. & Marwaha, R. 2023. Intellectual Disability. https://www.ncbi.nlm.nih.gov/books/NBK547654/

Lee, S., Cascella, M., & Marwaha, A. 2023. Causes of Intellectual Disabilities: An Overview. *Journal of Pediatric Neurology*, 41(1), 45-55.

Lund, C. 2020. Poverty and mental health: Towards a research agenda for low- and middle-income countries. *Social Psychiatry and Psychiatric Epidemiology*, 55(1):1-11.

Makofane, M.D.M. & Shirindi, M.L. 2018. The importance of data collection for qualitative research in social work. In: Shokane, A.L., Makhubele, J.C. & Blitz, L.V. (Eds). *Issues Around Aligning Theory, Research and Practice in Social Work Education* (Knowledge Pathing: Multi, Inter- and Trans-Disciplining in Social Sciences Series Volume 1). Cape Town: AOSIS.

Malterud, K., Siersma, V. & Guassora, A. 2016. Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research,* 26(13):1753-1760. doi: https//doi.org/1710.1177/1049732315617444

Marais, J.E., Wegner, L. & Mthembu, T. 2022. Support programmes for parents of children with intellectual disabilities: a scoping review protocol. *BMJ Open,* 12(1):1-5.

Maree, K. & Pietersen, J. 2020. Surveys and the use of questionnaires. In: Maree, K. (Ed.). *First steps in research.* 3rd ed. Pretoria: Van Schaik Publishers.

Masulani-Mwale, C., Kauye, F., Gladstone, M. & Mathanga, D. 2018. Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC Psychiatry,* 18(1):1-7.

Mbatha, N.L. & Mokwena, K.E. 2023. Parental Stress in Raising a Child with Developmental Disabilities in a Rural Community in South Africa. *International Journal of Environmental Research and Public Health*, *20*(5), 3969. https://doi.org/10.3390/ijerph20053969

Mbedzi, P. 2019. Ecosystems. In: Van Breda, A. & Sekudu, J. (Eds.). *Theories for decolonial social work practice in South Africa*. Cape Town: Oxford University Press.

McConnell, D. & Savage, A. 2015. Stress and resilience among families caring for children with intellectual disability: Expanding the research agenda. *Current Developmental Disorders Reports,* 2(2):100-109.

McKenzie, K., Milton, M., Smith, G. & Ouellette-Kuntz, H. 2016. Systematic Review of the Prevalence and Incidence of Intellectual Disabilities: Current Trends and Issues. *Current Developmental Disorders Reports,* 3(2):104-115. doi: https://doi.org/110.1007/s40474-40016-40085-40477

Mental Health Care Act 17 of 2002. (Published in the *Government Gazette,* (24024). Pretoria. Government Printer).

Mitter, N., Ali, A. & Scior, K. 2019. Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities,* 89 (1):10-21.

Mkabile, S. & Swartz, L. 2021. Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an African setting. *International Journal of Social Psychiatry,* 68(8).

Morrison, J. 2023. *DSM-5-TR: The clinician's guide to diagnosis.* New York, NY: Guilford Press.

Mphahlele, R., Makgahlela, M., & Ramolobe, S. 2020. Challenges faced by parents in caring for children with disabilities in rural South Africa. *Social Work/Maatskaplike Werk*, 56(2):145-157.

Muthukrishna, N., & Ebrahim, H. B. 2014. Mothering disabled children in the era of HIV and AIDS: A rural South African perspective. *Journal of Comparative Family Studies,* 45(3):415-431.

National Institute of Child Health and Human Development [NICHD]. 2021. *What Are Intellectual Disabilities?* Retrieved from https://www.nichd.nih.gov

Neal, J.W. & Neal, Z.P. 2013. Nested or networked? Future directions for ecological systems theory. *Social Development,* 22(4):722-737. doi: https://doi.org/710.1111/sode.12018

Nieuwenhuis, J. 2020a. Analysing qualitative data. In: Maree, K. (Ed.). *First steps in research*. 3rd ed. Pretoria: Van Schaik Publishers.

Nieuwenhuis, J. 2020b. Qualitative research designs and data-gathering techniques. In: Maree, K. (Ed.). *First steps in research.* 3rd ed. Pretoria: Van Schaik Publishers.

Norlin, D. & Broberg, M. 2013. Parents of children with and without intellectual disability: Couple relationship and individual well-being. *Journal of Intellectual Disability Research,* 57(6):552-566. doi: https://doi.org/510.1111/j.1365-2788.2012.01564.x

Nowell, L.S., Norris, J.M., White, D.E. & Moules, N.J. 2017. Thematic Analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods,* 16(1):1-13.

Padgett, D.K. 2017. *Qualitative methods in social work research*. 3rd ed. Thousand Oaks, CA: Sage.

Paruk, S. & Ramdhial, M. 2018. Prevalence of caregiver burden, depressive and anxiety symptoms in caregivers of children with psychiatric disorders in Durban, South Africa. *South African Journal of Psychiatry,* 20(24):1314. doi: 10.4102/sajpsychiatry.v24i0.1314. PMCID: PMC6191763.

Patton, K.A., Ware, R., McPherson, L., Emerson, E. & Lennox, N. 2018. Parent-related stress of male and female carers of adolescents with intellectual disabilities and carers of children within the general population: A cross-sectional comparison. *Journal of Applied Research in Intellectual Disabilities,* 31(1): 1-27.

Peer, J.W. & Hillman, S.B. 2014. The mediating impact of coping style on stress perception for parents of individuals with intellectual disabilities. *Journal of Intellectual Disabilities,* 16(1):45-59.

Perinatal Mental Health Project [PMHP]. 2023. *Mental Health and Pregnancy: Addressing Challenges for Low-Income Women*. Retrieved from https://www.pmhp.org

Perron, N. 2017. Bronfenbrenner's ecological systems theory. In: Killam, W.K. & Degges-White, S. (Eds.). *College student development: Applying theory to practice on the diverse campus*. New York, NY: Springer.

Pilapil, M., Coletti, D. J., Rabey, C., & DeLaet, D. 2017. Caring for the caregiver: Supporting families of youth with special health care needs. *Current Problems in Pediatric and Adolescent Health Care, 47*(8), 190-199.

Pinilis, L. 2011. *A Biblical View of Time: Shifting from Chronos to Kairos.* https://www.lifeofasteward.com/chronos-kairos/

Roestenburg, W.J.H. & Strydom, H. 2021. Intervention research. In: Fouché, C.B. (Ed.)., Strydom, H. & Roestenburg, W.J.H. *Research at the grassroots: For the social sciences and human service professions.* 5th ed. Pretoria: Van Schaik Publishers.

Rubin, A. & Babbie, E. 2017. *Research methods for social work.* 9th ed. Boston, MA: Cengage Learning.

Ryan, G. 2018. Introduction to positivism, interpretivism and critical theory. *Nurse Researcher*, 25(4):14-20. doi: https://doi.org/10.7748/nr.2018.e1466

Salomon, C., Britt, H., Pollack, A. & Trollor, J. 2018. Primary care for people with an intellectual disability – what is prescribed? An analysis of medication recommendations from the BEACH dataset. *BJGP Open,* 1(1): 1-9.

Sankey, C., Derguy, C., Clement, C., Ilg, J. & Cappe, E. 2019. Supporting parents of a child with autism spectrum disorder: The French awakening. *Journal of Autism and Developmental Disorders,* 4(3):1142-1153.

Schurink, W.J., Schurink, E.M. & Fouché, C.B. 2021b. Thematic inquiry in qualitative research. In: Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (Eds.). *Research at the grassroots: For the social sciences and human service professions*. 5th ed. Pretoria: Van Schaik Publishers.

Scior, K. 2016. *Global Perspectives on Intellectual Disabilities: A Sociocultural Approach.* Cambridge University Press.

Scior, K. & Werner, S. (Eds.). 2016. *Intellectual Disability and Stigma: Stepping Out from the Margins.* Palgrave Macmillan UK.

Shokane, A.L., Makhubele, J.C. & Blitz, L.V. (Eds). 2018. *Issues Around Aligning Theory, Research and Practice in Social Work Education* (Knowledge Pathing: Multi, Inter- and Trans-Disciplining in Social Sciences Series Volume 1). Cape Town: AOSIS.

Singh, S. & Wassenaar, D.R. 2016. Contextualising the role of the gatekeeper in social science research. *South African Journal of Bioethics and Law,* 9(1):42-46. doi: https://doi.org/10.7196/SAJBL.2016.v7199i7191.7465

South African Council for Social Service Professions. 2025. Social Work. https://www.sacssp.co.za/for-the-profession-social-work/

Spaull, N. 2019. Equity: A blind spot in South Africa’s education policies. *Journal of Education*, 74(1):75-97.

Statistics South Africa. 2021. *Families and parents are key to the well-being of children*. https://www.statssa.gov.za/?p=14388

Strydom, H. 2021. Sampling techniques and pilot studies in qualitative research. In: Fouché, C.B. (Ed.)., Strydom, H. & Roestenburg, W.J.H. *Research at the grassroots: For the social sciences and human service professions.* 5thed. Pretoria: Van Schaik.

Scior, K. (2016). *Global Perspectives on Intellectual Disabilities: A Sociocultural Approach*. Cambridge University Press.

Smiley, J. 2024. *Intellectual Disability: Signs, Causes and Support*. https://www.verywellhealth.com/types-of-intellectual-disability-in-children-and-adults-5210316

Stuttard, L., Beresford, B., Clark, S., Beecham, J., Todd, S. & Bromley, J. 2014. Riding the Rapids: living with autism or disability - an evaluation of a parenting support intervention for parents of disabled children. *Research in Developmental Disabilities,* 35(10):2371-2383.

Sunshine Association. 2024. *Hope for children with disabilities.* https://sunshine.org.za/

Taylor, S., Wright, A.C., Pothier, H., Hill, C. & Rosenberg, M. 2019. It's Like I Have an Advantage in All This: Experiences of Advocacy. It's Like I Have an Advantage in All This: Experiences of Advocacy by Parents of Children with Disabilities from Professional Backgrounds. *The Journal of Sociology & Social Welfare,* 46(3):159-183.

Tenny, S., Brannan, J.M. & Brannan, G.D. 2022. *Qualitative Study*. https://www.ncbi.nlm.nih.gov/books/NBK470395/

The Constitution of the Republic of South Africa, 1996. https://www.refworld.org/docid/3ae6b5de4.html

The Down Syndrome Association Gauteng. 2024. https://tdsag.co.za/

Thomas, K., Nilsson, E., Festin, K., Henriksson, P., Lowen, M, Lof, M. & Kristenson, M. 2020. Associations of psychosocial factors with multiple health behaviours: a population-based study of middle-aged men and women. *International Journal of Environmental Research and Public Health,* 17(1):2-17.

Tyrrell, P., Harberger, S., Schoo, C. & Siddiqui, W. 2023. *Kubler-Ross Stages of Dying and Subsequent Models of Grief.* https://www.ncbi.nlm.nih.gov/books/NBK507885/

Vorster, A. 2019. Neurodevelopmental and other childhood disorders. In: Burke, A., Austin, T.-L., Bezuidenthout, C., Botha, K., Du Plessis, E., Jordaan, E., Lake, M., Makhafula, K., Makhubela, M., Moletsane, M., Nel, J.A., Pillay, B., Stein, D.J., Ure, G., Von Krosigk, B. & Vorster, A. (Eds.). *Understanding psychopathology: South African perspectives*. 3rd ed. Cape Town: Oxford University Press.

Werlen, L., Gjukaj, D., Mohler-Kuo, M. & Puhan, M.A. 2019. Interventions to improve children's access to mental health care: a systematic review and meta-analysis. *Epidemiology and Psychiatric Sciences,* 29(1):1-27.

White Paper on the Rights of Persons with Disabilities. 2016. (Published in the *Government Gazette*, (39792). Pretoria: Government Printer).

Woodman, A. C., Mawdsley, H. P. & Hauser-Cram, P. 2015. Parenting stress and child behaviour problems within families of children with developmental disabilities:

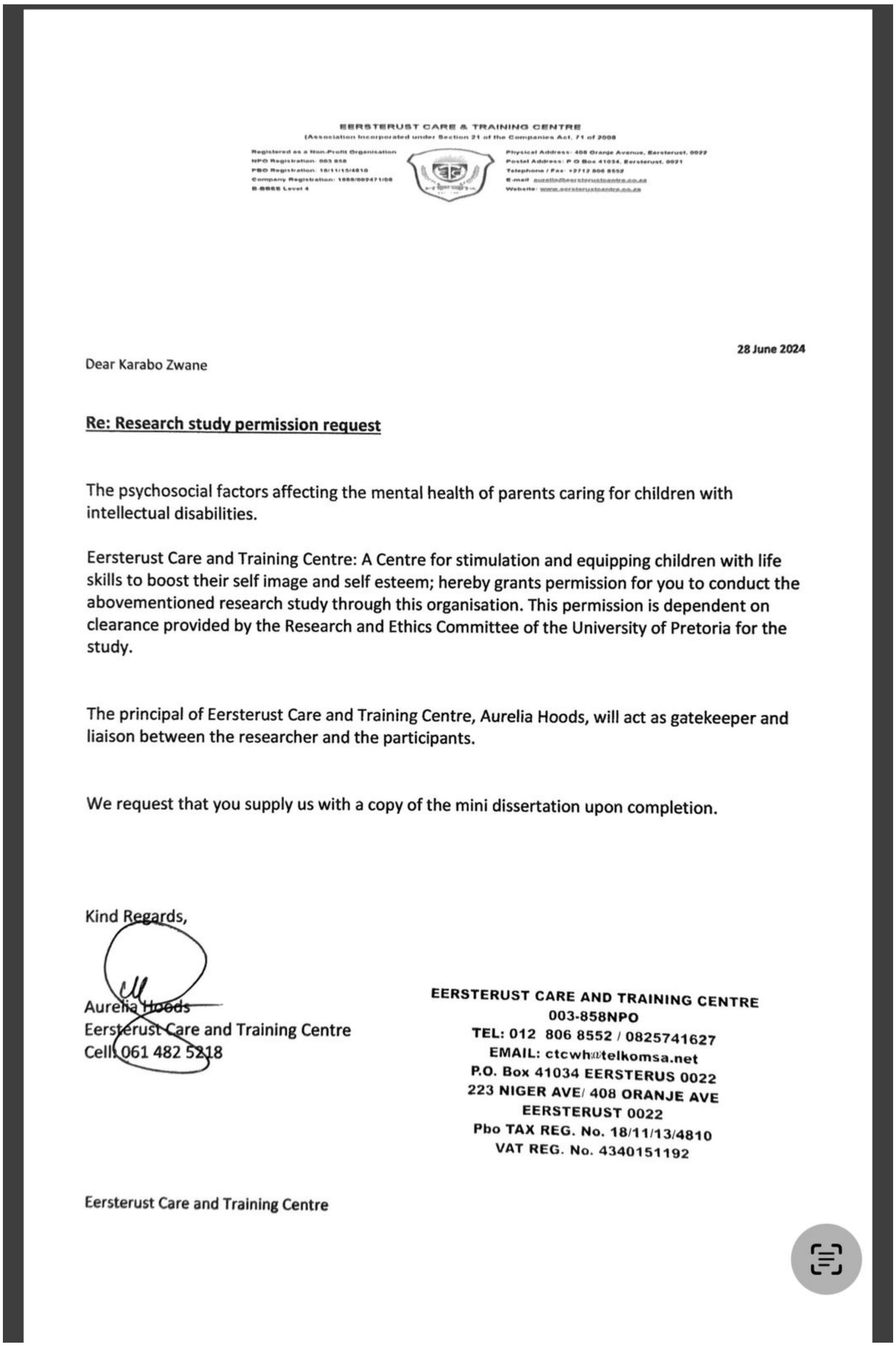
Transactional relations across 15 years. *Research in developmental disabilities*, 36(1), 264–276.

World Health Organisation. 2022. *Mental Health*. https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response

World Health Organisation. 2023. *Mental Health.* https://www.who.int/health-topics/mental-health#tab=tab_2

APPENDICES

Appendix 1: Permission for empirical study from Eersterust Care and Training Centre



EERSTERUST CARE & TRAINING CENTRE
(Association Incorporated under Section 21 of the Companies Act, 71 of 2008

Registered as a Non-Profit Organisation
NPO Registration: 003 858
PBO Registration: 18/11/13/4810
Company Registration: 1988/002471/08
B-BBEE Level 4

Physical Address: 408 Oranje Avenue, Eersterust, 0022
Postal Address: P O Box 41034, Eersterust, 0021
Telephone / Fax: +2712 806 8552
E-mail: aurelia@eersterustcentre.co.za
Website: www.eersterustcentre.co.za

28 June 2024

Dear Karabo Zwane

<u>Re: Research study permission request</u>

The psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities.

Eersterust Care and Training Centre: A Centre for stimulation and equipping children with life skills to boost their self image and self esteem; hereby grants permission for you to conduct the abovementioned research study through this organisation. This permission is dependent on clearance provided by the Research and Ethics Committee of the University of Pretoria for the study.

The principal of Eersterust Care and Training Centre, Aurelia Hoods, will act as gatekeeper and liaison between the researcher and the participants.

We request that you supply us with a copy of the mini dissertation upon completion.

Kind Regards,

Aurelia Hoods
Eersterust Care and Training Centre
Cell: 061 482 5218

EERSTERUST CARE AND TRAINING CENTRE
003-858NPO
TEL: 012 806 8552 / 0825741627
EMAIL: ctcwh@telkomsa.net
P.O. Box 41034 EERSTERUS 0022
223 NIGER AVE/ 408 ORANJE AVE
EERSTERUST 0022
Pbo TAX REG. No. 18/11/13/4810
VAT REG. No. 4340151192

Eersterust Care and Training Centre

Appendix 2: Approval from Ethics Committee, University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100.
Since 1919

03 July 2024

Dear Mrs KP Zwane

Project Title:	Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Pretoria
Researcher:	Mrs KP Zwane
Supervisor(s):	Prof NJ Bila
Department:	Social Work and Criminology
Reference number:	16220154 (HUM050/0524)
Degree:	Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 03 July 2024. Please note that before research can commence all other approvals must have been received.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Karen Harris
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

Room 7-27, Humanities Building, University of Pretoria, Private Bag X20, Hatfield 0028, South Africa
Tel +27 (0)12 420 4853 | Fax +27 (0)12 420 4501 | Email: pghumanities@up.ac.za | www.up.ac.za/faculty-of-humanities

Appendix 3: Participant Information Sheet

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Department of Social Work & Criminology

Humanities 100.
Since 1919

29 April 2025
Researcher: Karabo Zwane
Contact number: +27 61 058 4059
E-mail: u16220154@tuks.co.za
Supervisor: Prof NJ Bila
Contact details: 012-420-2599
Email: Nontembeko.Bila@up.ac.za

STUDY INFORMATION SHEET

Title of study: Exploring the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities in Eersterust.

Dear Participant,

Karabo Zwane is a postgraduate student with a Master of Social Work (MSW) in Healthcare at the University of Pretoria. As part of the degree's requirements, she has to conduct a research project and write up the findings in a mini-dissertation, which will be submitted for examination purposes. The research study aims to explore the psychosocial factors affecting the mental health of parents caring for children with ID in Eersterust.

As a parent caring for a child with an intellectual disability, you have been approached by the gatekeeper of the organisation Eersterust Care and Training Centre, Ms. Aurelia Hoods, as a potential participant to participate in the abovementioned research study. Thank you for your time and consideration of participation in this research study.

Participation will require your availability to partake in a one-on-one interview of approximately 45 minutes to 1 hour, at a time and place that is convenient for you. Karabo Zwane, the researcher who will interview you, is a qualified social worker, registered with the South African Council for Social Services Professions (SACSSP). An interview guide will guide the interview, and everything discussed with you will be kept confidential. You will also be assigned a false name or pseudonym, instead of using your real name to protect your identity.

Room 10-5Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2325/2599
Email Nontembeko.Bila@up.ac.za | www.up.ac.za

The information you share will be voice recorded with your permission to make data collection easier and more accurate. After the interview, the recorded data will be transcribed into written form and analysed for research purposes. This data will be used for research purposes and only accessible to the researcher and supervisor. Participation in this study is voluntary and you can withdraw from participating in the interview at any time if you choose to, with no consequences.

The researcher will answer any questions you might have regarding the study and interview before you decide to participate. If you are interested in partaking in this study, please provide the gatekeeper with your contact details in the space below so that the researcher can contact you. Alternatively, the researcher's contact details are available below, should you wish to contact the researcher directly.

Name: ____

Phone: ____

Email:____

Yours sincerely,

Karabo Zwane

Researcher

Contact number: 061 058 4058

Email: u16220154@tuks.co.za

Prof. N. Bila

Supervisor

Room 10-21.1, Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2325/2599
Email Nontembeko.Bila@up.ac.za | www.up.ac.za

Appendix 4: Participant Letter of Informed Consent

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Department of Social Work & Criminology

Humanities 100.
Since 1919

29 April 2025
Researcher: Karabo Zwane
Contact number: +27 61 058 4059
E-mail: u16220154@tuks.co.za
Supervisor: Prof NJ Bila
Contact details: 012-420-2599
Email: Nontembeko.Bila@up.ac.za

INFORMED CONSENT FORM

Section A: Research Information

This letter invites you to participate in a research study on: Exploring the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities in Eersterust. This letter briefly explains the study's purpose, procedures, risks, and benefits. The letter further outlines the rights of participants and confidentiality. Please read carefully through the document to make an informed decision regarding your voluntary participation. Please note that participation or non-participation will not affect your access to services at Eersterust Care and Training Centre. You are welcome to ask questions about the proposed study before signing the consent form.

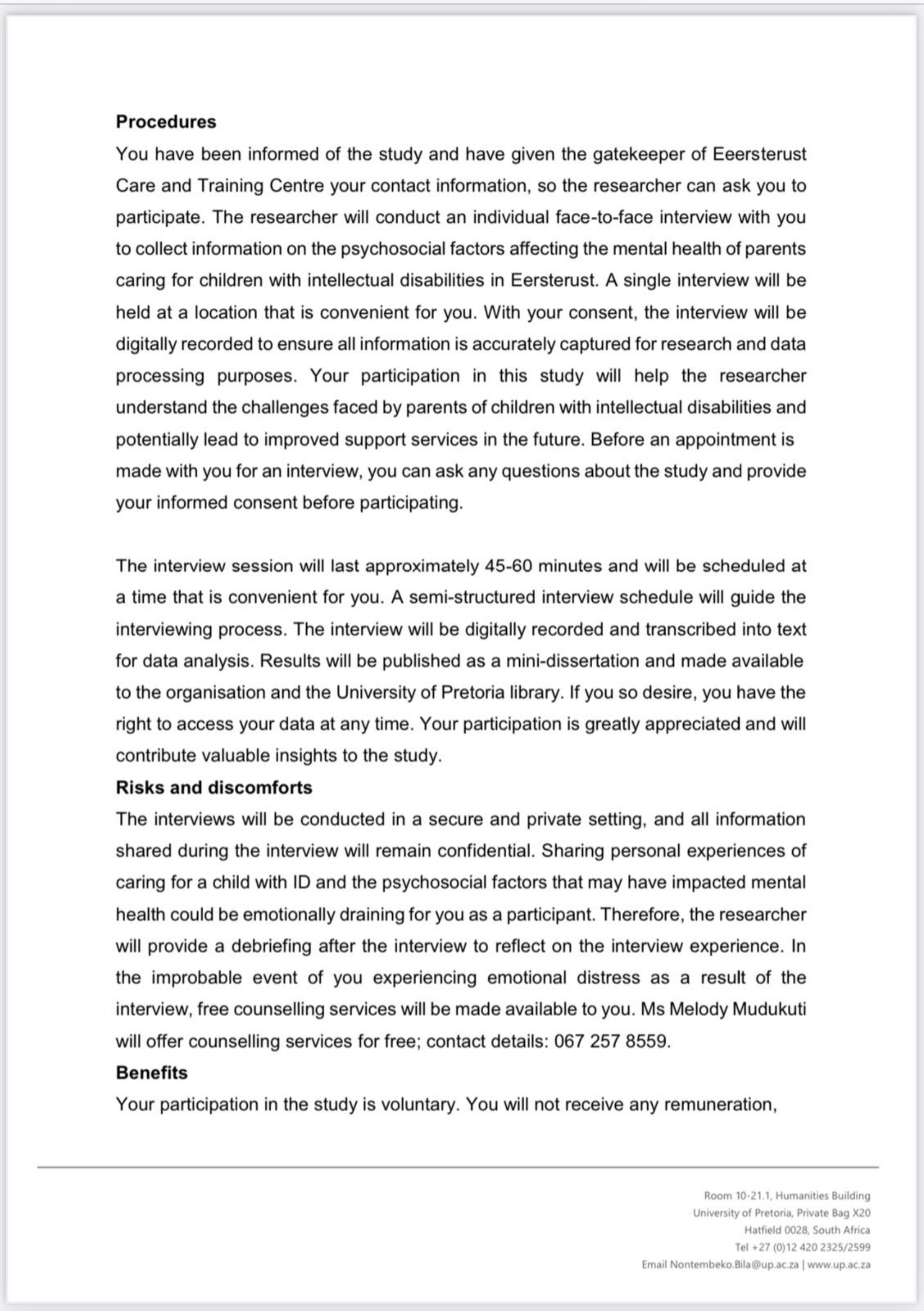
Title of the study

Exploring the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities in Eersterust.

Purpose of the study

The purpose of the study is to explore the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities in South Africa. The study will examine the experiences of parents living in Eersterust.

Room 10-5Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2325/2599
Email Nontembeko.Bila@up.ac.za | www.up.ac.za



Procedures

You have been informed of the study and have given the gatekeeper of Eeersterust Care and Training Centre your contact information, so the researcher can ask you to participate. The researcher will conduct an individual face-to-face interview with you to collect information on the psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Eersterust. A single interview will be held at a location that is convenient for you. With your consent, the interview will be digitally recorded to ensure all information is accurately captured for research and data processing purposes. Your participation in this study will help the researcher understand the challenges faced by parents of children with intellectual disabilities and potentially lead to improved support services in the future. Before an appointment is made with you for an interview, you can ask any questions about the study and provide your informed consent before participating.

The interview session will last approximately 45-60 minutes and will be scheduled at a time that is convenient for you. A semi-structured interview schedule will guide the interviewing process. The interview will be digitally recorded and transcribed into text for data analysis. Results will be published as a mini-dissertation and made available to the organisation and the University of Pretoria library. If you so desire, you have the right to access your data at any time. Your participation is greatly appreciated and will contribute valuable insights to the study.

Risks and discomforts

The interviews will be conducted in a secure and private setting, and all information shared during the interview will remain confidential. Sharing personal experiences of caring for a child with ID and the psychosocial factors that may have impacted mental health could be emotionally draining for you as a participant. Therefore, the researcher will provide a debriefing after the interview to reflect on the interview experience. In the improbable event of you experiencing emotional distress as a result of the interview, free counselling services will be made available to you. Ms Melody Mudukuti will offer counselling services for free; contact details: 067 257 8559.

Benefits

Your participation in the study is voluntary. You will not receive any remuneration,

compensation, or incentives for participating in the study. The study is about exploring the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities. The findings of this study can inform social workers and other professionals about their interventions in rendering services to parents of children with intellectual disabilities.

Participants rights

Your participation is voluntary; you will not be forced to participate and can refuse or withdraw at any time without giving a reason or facing consequences. If you decide to withdraw, all information shared during the interview will be destroyed.

Confidentiality and anonymity

All information disclosed in the interview will remain confidential and only be used for research purposes. As the interview will be face-to-face, anonymity cannot be ensured. To protect your identity, your identity will be kept confidential and de-identified by using a pseudonym or false name when data is analysed and reported. Only the researcher and supervisor will have access to the confidential data.

Data storage and usage

Please note that the data collected might be used for a journal publication, a conference paper, and possibly further research in the future. The data collected will be kept confidential and stored in a password-protected format in the Department of Social Work and Criminology, University of Pretoria for a period of 10 years as required.

Access to the researcher

If there are any questions or inquiries about the study, please do not hesitate to contact the researcher at:

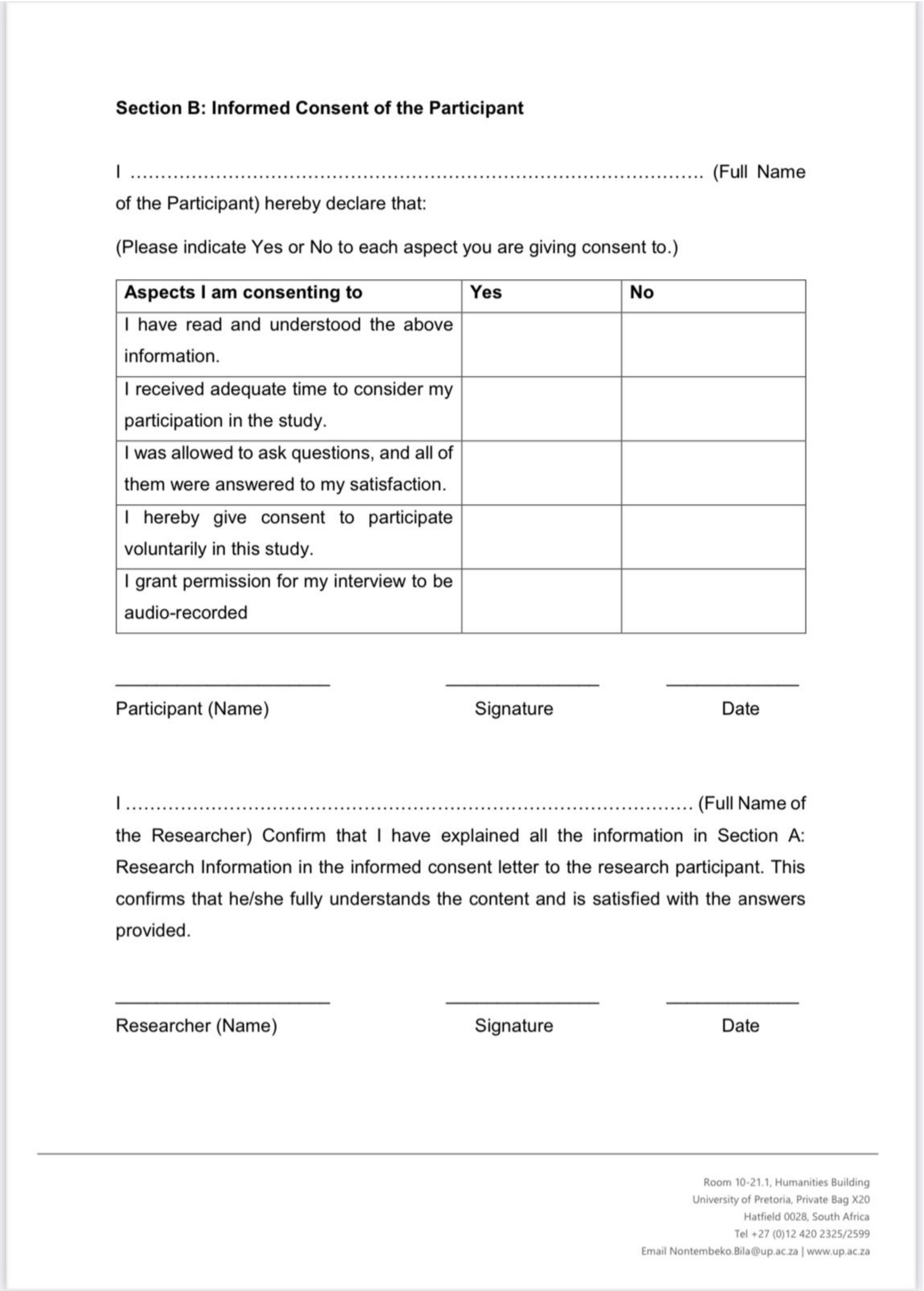
Name: Karabo Princess Zwane
Cell: +27 61 058 4059
Email: u16220154@tuks.co.za

Please sign section B on the next page to consent to participate in this study.

Yours sincerely,

Karabo Zwane	Prof. N. Bila
Researcher	Supervisor

Room 10-21.1, Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2325/2599
Email Nontembeko.Bila@up.ac.za | www.up.ac.za



Section B: Informed Consent of the Participant

I ……………………………………………………………………………………. (Full Name of the Participant) hereby declare that:

(Please indicate Yes or No to each aspect you are giving consent to.)

Aspects I am consenting to	**Yes**	**No**
I have read and understood the above information.		
I received adequate time to consider my participation in the study.		
I was allowed to ask questions, and all of them were answered to my satisfaction.		
I hereby give consent to participate voluntarily in this study.		
I grant permission for my interview to be audio-recorded		

______________________ ________________ ______________

Participant (Name) Signature Date

I ………………………………………………………………………………… (Full Name of the Researcher) Confirm that I have explained all the information in Section A: Research Information in the informed consent letter to the research participant. This confirms that he/she fully understands the content and is satisfied with the answers provided.

______________________ ________________ ______________

Researcher (Name) Signature Date

Room 10-21.1, Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2325/2599
Email Nontembeko.Bila@up.ac.za | www.up.ac.za

Appendix 5: Free counselling services letter

14 May 2024

The Chair: Prof K Harris
ResEthics Committee
Faculty of Humanities
University of Pretoria

To whom it may concern

I, Melody T. Mudukuti hereby confirm that I will provide counselling free of charge for the participants of the above-mentioned study, conducted by the MSW (Healthcare) student, should there be a need following the research interview.

Title of the study: *The psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities.*
My details are as follows:

Name: Melody T. Mudukuti

Qualification: Social Worker

Contact details: 067 257 8559

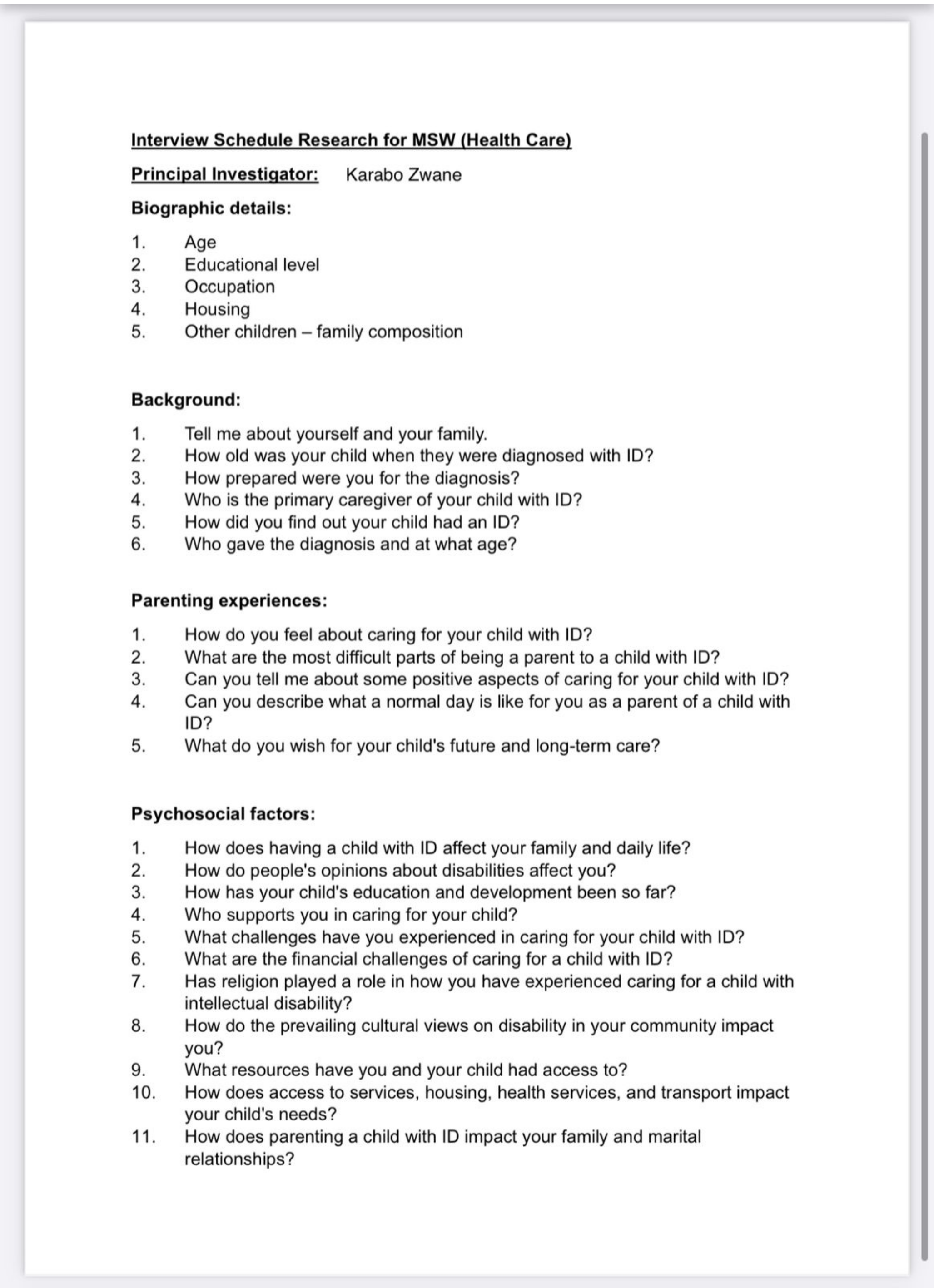
Registration Board: South African Council for Social Services Professions

Registration Number: 1057504

Kind regards,

M. T. Mudukuti

Appendix 6: Interview schedule



Interview Schedule Research for MSW (Health Care)

Principal Investigator: Karabo Zwane

Biographic details:

1. Age
2. Educational level
3. Occupation
4. Housing
5. Other children – family composition

Background:

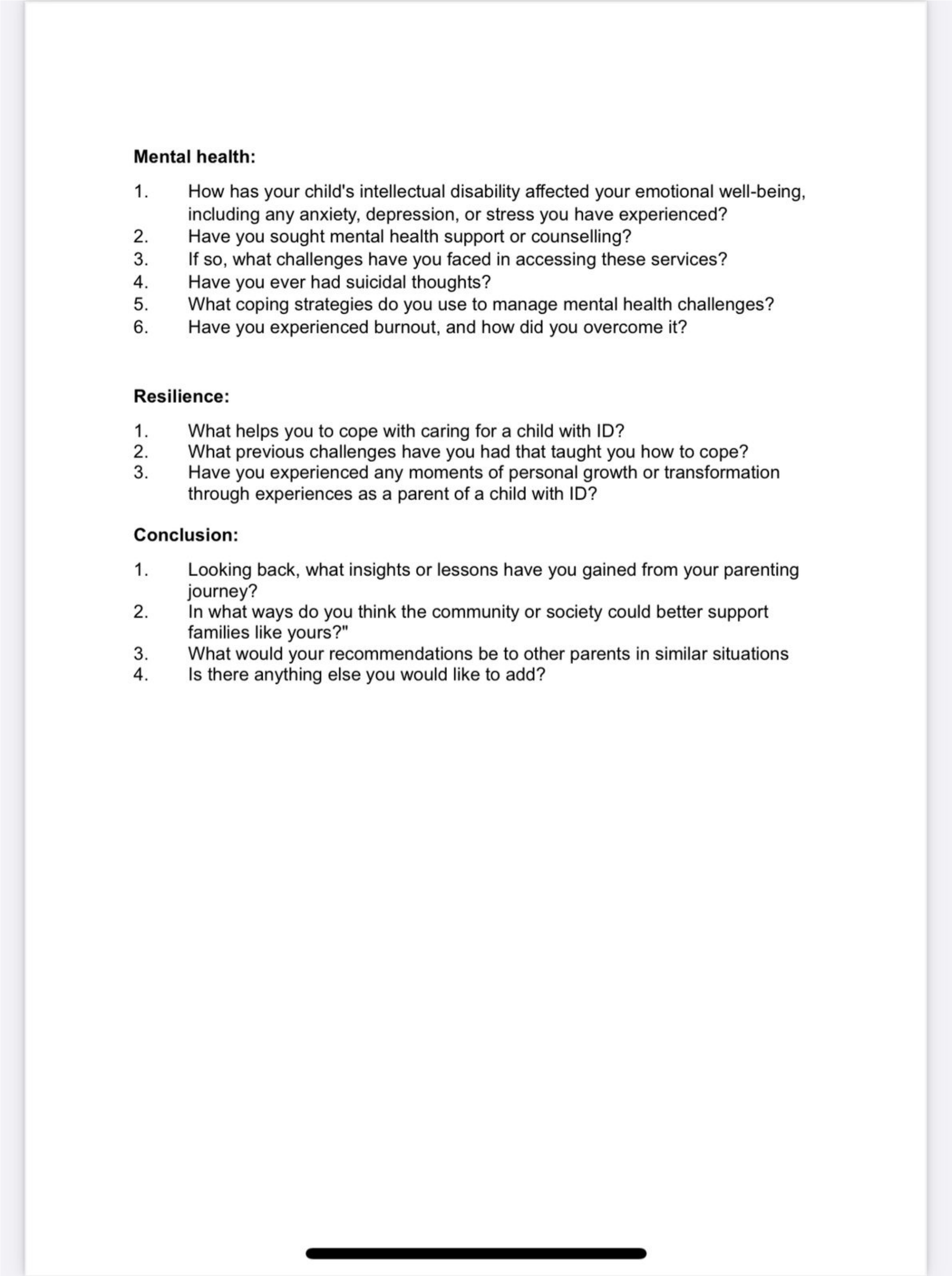
1. Tell me about yourself and your family.
2. How old was your child when they were diagnosed with ID?
3. How prepared were you for the diagnosis?
4. Who is the primary caregiver of your child with ID?
5. How did you find out your child had an ID?
6. Who gave the diagnosis and at what age?

Parenting experiences:

1. How do you feel about caring for your child with ID?
2. What are the most difficult parts of being a parent to a child with ID?
3. Can you tell me about some positive aspects of caring for your child with ID?
4. Can you describe what a normal day is like for you as a parent of a child with ID?
5. What do you wish for your child's future and long-term care?

Psychosocial factors:

1. How does having a child with ID affect your family and daily life?
2. How do people's opinions about disabilities affect you?
3. How has your child's education and development been so far?
4. Who supports you in caring for your child?
5. What challenges have you experienced in caring for your child with ID?
6. What are the financial challenges of caring for a child with ID?
7. Has religion played a role in how you have experienced caring for a child with intellectual disability?
8. How do the prevailing cultural views on disability in your community impact you?
9. What resources have you and your child had access to?
10. How does access to services, housing, health services, and transport impact your child's needs?
11. How does parenting a child with ID impact your family and marital relationships?



Mental health:

1. How has your child's intellectual disability affected your emotional well-being, including any anxiety, depression, or stress you have experienced?
2. Have you sought mental health support or counselling?
3. If so, what challenges have you faced in accessing these services?
4. Have you ever had suicidal thoughts?
5. What coping strategies do you use to manage mental health challenges?
6. Have you experienced burnout, and how did you overcome it?

Resilience:

1. What helps you to cope with caring for a child with ID?
2. What previous challenges have you had that taught you how to cope?
3. Have you experienced any moments of personal growth or transformation through experiences as a parent of a child with ID?

Conclusion:

1. Looking back, what insights or lessons have you gained from your parenting journey?
2. In what ways do you think the community or society could better support families like yours?"
3. What would your recommendations be to other parents in similar situations
4. Is there anything else you would like to add?

Appendix 7: Change of Research Title

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

RECOMMENDATION REGARDING TITLES OF THESES/DISSERTATIONS/MINI-DISSERTATIONS,

APPOINTMENT OF SUPERVISORS/CO-SUPERVISORS

THIS FORM MUST PLEASE BE TYPED AND SUBMITTED TO THE RESEARCH ETHICS / POSTGRADUATE COMMITTEE.

Student number: **16220154** Title: **Mrs**

Surname: **Zwane** Initials: **K.P**

Course e.g. MA(Anthropology): **MSW Healthcare**

Department: **Social Work and Criminology**

Date of ethical clearance: **03/07/2024**

Ethics protocol number: **HUM050/0524**

Please ensure that the title is grammatically correct.
Please do not type the full title in capital letters.

For notification of the faculty board, please mention:

THESIS:
DISSERTATION: _____
MINI-DISSERTATION: ____ **X**

Current research title:

Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Pretoria

New research title (to be approved):

Exploring the psychosocial factors influencing the mental health of parents caring for children with intellectual disabilities in Eersterust

a) SUPERVISOR:
Please state staff number
(If a person outside the University is nominated, a CV and motivation should be attached to the proposal)

Prof NJ Bila
23189259

b) CO-SUPERVISOR:
Please state staff number
(If a person outside the University is nominated, a CV and motivation should be attached to the proposal)

Not applicable.

ROUTE

1. SUPERVISOR:

Signature:

Date: **20/11/2024**

2. DEPARTMENTAL RESEARCH/POSTGRADUATE COMMITTEE:

Signature

Date: 22/11/2024.........................

3. HEAD OF DEPARTMENT:

Signature...............................
28 /11/2024
Date.............................

4. FACULTY RESEARCH ETHICS/ POSTGRADUATE COMMITTEE:
Where applicable (to approve research proposal/ethics; change of title; appointment or change of internal/external supervisor/co-supervisor;

Signature...............................

Date...29 Nov 2024.........

5. STUDENT ADMINISTRATION:

Signature...............................

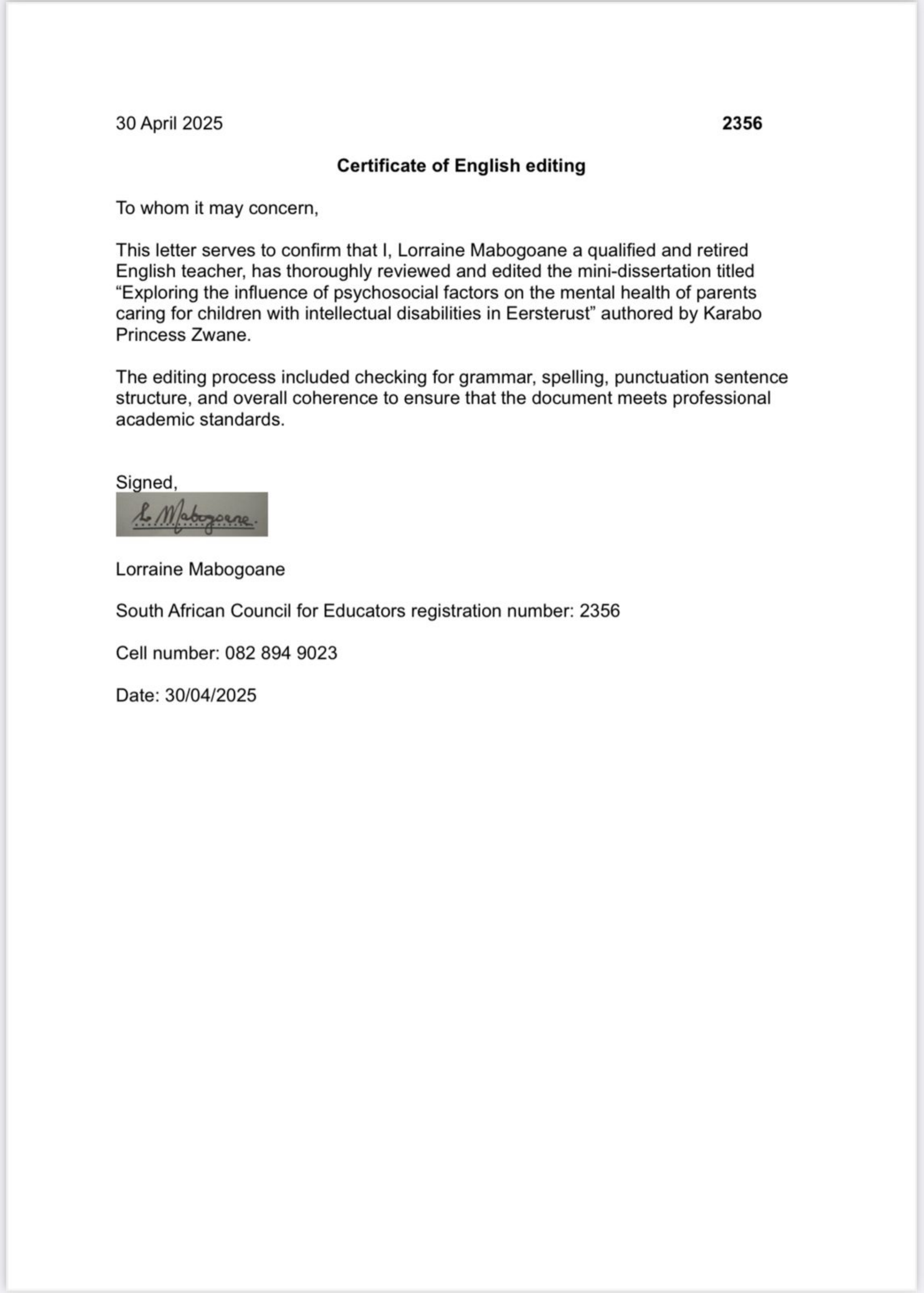
Date.............................

APPROVAL:

- ☐ Ethical clearance to be considered by the Ethics Committee
- ☐ Appointment of external supervisor/co-supervisor (motivation and cv attached)
- ☐ Change of supervisor/co-supervisor
- ☐ Research proposal and title to be considered by the Postgraduate Committee (where applicable)
- ☑ **Editorial change of title**
- ☐ Other (mention): ____________________________________

August 2017 - Faculty of Humanities Postgraduate Committee and Ethics Committee

Appendix 8: Letter from the Editor



30 April 2025 **2356**

Certificate of English editing

To whom it may concern,

This letter serves to confirm that I, Lorraine Mabogoane a qualified and retired English teacher, has thoroughly reviewed and edited the mini-dissertation titled “Exploring the influence of psychosocial factors on the mental health of parents caring for children with intellectual disabilities in Eersterust” authored by Karabo Princess Zwane.

The editing process included checking for grammar, spelling, punctuation sentence structure, and overall coherence to ensure that the document meets professional academic standards.

Signed,
L Mabogoane

Lorraine Mabogoane

South African Council for Educators registration number: 2356

Cell number: 082 894 9023

Date: 30/04/2025