Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng

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Vita, Via, Veritas!

ABSTRACT

Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng

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DEGREE: MSW Healthcare

INSTITUTION: University of Pretoria

Intellectual disabilities are prevalent across the globe. Children with intellectual disabilities require specialised services from a multidisciplinary team to ensure optimal development and quality of life. Traditionally these services focus on children themselves and not their family and caregivers. Numerous studies have established the link between parental well-being and the child's well-being, emphasising that the services reaching beyond the child to the family of children with intellectual disability will benefit the child, sibling and parents, ensuring quality of life for all members.

The goal of the study was to explore the psychosocial factors affecting the mental health of parents caring for children with intellectual disability in Benoni, Gauteng. Using the ecosystem perspective as a theoretical framework, the researcher aimed to explore the parent's experience of the psychosocial factors affecting their mental health.

The researcher utilised a qualitative approach with an instrumental case study, which allowed the researcher to explore the phenomenon of psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in-depth. The study population was parents caring for their children with intellectual disabilities under the age of 18 years, who are utilising the services of Apricot Tree Centre in Benoni. One-on-one semi-structured interviews, an interview schedule and recordings were used to collect data for this study. The interviews were transcribed, and Reflexive Thematic Analysis was used to inductively identify themes and sub-themes from the data to answer the following research question: What are the psychosocial factors affecting the mental health of parents caring for children with ID in Benoni, Gauteng?

The findings revealed that factors impacting the mental health of participants varied throughout the different phases of diagnosis and the mental distress often starts long before diagnosis. The nuclear family are the most profoundly affected by caring for a

child with intellectual disability, providing the most significant challenges and most significant support. The caregiver's responsibility profoundly impacts the mental health of participants and is the most likely factor to lead to burnout and a mental health crisis. The loss of parental roles due to overwhelming caregiver responsibility significantly impacts the participants' view of self, leaving them vulnerable to feelings of loss and failure. This, together with societal views and stigmatisation shapes the participants' core beliefs. Various external structures such as family, religion, culture and society intensify the pressure and mental health challenges for the participants, as stigmatisation and cultural values leave participants feeling isolated and alone, negatively impacting their mental health.

Despite all these challenges participants have achieved a sense of meaning and purpose in caring for their child with intellectual disabilities. Finding meaning and purpose, reframing hopes and dreams, drawing on support, spirituality and effective coping strategies, contribute to the mental health resilience of participants.

The recommendations that emerged from this study include: providing specialised mental health support for parents caring for children with intellectual disabilities; adopting a multidisciplinary approach in service delivery and intervention that supports the entire family of children with intellectual disabilities; advocacy and education within communities, churches, and families to facilitate inclusive mindsets, not just policies, around intellectual disabilities; and implementing early interventions to support families caring for children with intellectual disabilities.

Viewing this study as part of a larger study from the MSW Healthcare 2023 group, will allow a broader picture of this phenomenon across different populations in different locations in South Africa. Although this study was successful in meeting the aims and objectives, further research on this phenomenon will be valuable to social work services. Research into the impact of behavioural challenges in children with intellectual disabilities on parental isolation, and the lack of informal social support is recommended. Furthermore, the researcher recommends exploring the role of early psychosocial interventions in caring for children with intellectual disabilities to improve coping and resilience in these parents and understand the specialized mental health and support services that families caring for children with intellectual disabilities require.

Key concepts:

Children

Intellectual disability

Mental health

Parents

Psychosocial factors

Social work

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CHAPTER 1
GENERAL INTRODUCTION

1.1 INTRODUCTION AND CONTEXTUALISATION

Intellectual disabilities (ID) have a staggering effect on the life of the individual, family, friends, and community. The severity of ID ranges from mild to severe. Many children with mild ID will mature to be independent and self-sufficient adults, while others will require continuous care throughout their lives. Irrespective of the severity of the ID, caring for a child with ID (CWID) can be a stressful and complex task for a parent, while also a very rewarding task. Previous studies and an understanding of the ecosystems perspective, clearly indicate the link between child well-being and parental well-being, highlighting the importance of services for the child and parents (Hatton & Emerson, 2015:23; Staunton, Kehoe & Sharkey, 2020:1). The well-being of a parent directly influences the well-being of the child, and similarly the well-being of a child has a direct impact on the mental health (MH) of a parent (Eddy, 2013a:142). Information gathered during this study will help social workers to tailor services for CWID and their families, specifically in the urban context in South Africa.

Various factors affecting the MH of parents caring for CWID have been highlighted in previous studies, including anxiety, stress, depression, care burden, and stigmatisation (Hanson, 2013:98; Islam, Rahman & Akhar, 2022:216; Staunton et al., 2020:5). Positive factors include social support, family cohesion, spirituality and resilience (Masulani-Mwale, Mathanga, Silungwe, Kauye & Gladstone, 2016:872; Mazzucchelli, Wilker & Sanders, 2019:743). In Africa, parents caring for CWID experience unique psychosocial factors that can affect their MH, such as cultural stigmatisation, financial distress and lack of access to services (Masulani-Mwale et al., 2016:876–877). The recent deterioration in basic services such as water, electricity and housing will also be explored as one of the unique factors impacting parents of CWID in Benoni, Gauteng (Thusi & Selepe, 2023:695). This study will explore the psychosocial factors impacting the MH of parents caring for CWID at a private care facility in Benoni, Gauteng.

The definitions used during this study for key concepts are as follows:

- **Child/children:** In South Africa's Children's Act "Child means a person under the age of 18 years" (Republic of South Africa, 2006). The operational definition for a child in this study is any person under the age of 18 years.
- **Intellectual disability:** Intellectual disability (ID) refers to a disability with significant limitations in intellectual functioning and adaptive abilities with onset before the age of 18 (Cervantes, Shalev & Donnelly, 2019:49; Patel, Greydanus, Merrick & Rubin, 2016:5, 6). These limitations in adaptive behaviour are visible in conceptual, social and practical adaptive abilities (Patel et al., 2016:35). For this study ID is viewed as mild to profound limitations in intellectual and cognitive functioning.
- **Mental health:** Mental health (MH) refers to "a state of mind characterised by emotional well-being, good behavioural adjustment, relative freedom from anxiety and disabling symptoms, and a capacity to establish constructive relationships and cope with the ordinary demands and stresses of life" (American Dictionary of Psychology [APA], 2024a). According to The World Health Organisation (WHO) (WHO, 2022) MH varies according to individuals' unique circumstances. For this study, mental health refers to the individual's perception of mental well-being.
- **Parent:** According to the South African Schools Act 84 of 1996 "parent" means—

  > "(a) the biological or adoptive parent or legal guardian of a learner;
  > (b) the person legally entitled to custody of a learner; or
  > (c) the person who undertakes to fulfil the obligations of a person referred to in paragraphs (a) and (b) towards the learner's education at school;" (Republic of South Africa, 1996).

  The operational definition of a parent is a caregiver or legally recognised parent involved in the daily care and decision-making of the child.

- **Psychosocial factors:** psychosocial factors are "the intersection and interaction of social, cultural, and environmental influences on the mind and behaviour" (APA, 2024a). Psychosocial factors are thus conceptualised as psychological, social, cultural, and environmental factors interacting with one another in a manner that affects a person's MH.

1.2 THEORETICAL FRAMEWORK

This research will be conducted from an Ecological Systems Perspective (ESP). The ESP assumes that no person can be viewed in isolation, but is influenced by the interaction between the biological, relational, physical, environmental and social aspects of the individual's life (Teater, 2021:48).

Bertalanffy's work in the 1960s introduced the idea of a systems theory into natural science, arguing that all parts are interrelated rather than driven by cause-and-effect (Langer, 2014:28). The systems theory was later adapted to social science in the form of the family systems theory, and in 1986 Bronfenbrenner developed the ESP from the perspective of child development (Langer, 2014:29–30). Bronfenbrenner's work has been widely accepted and applied within social work.

The ESP seeks to understand the interaction between a person and their environment through five different systems within the individual's life, the micro-, meso-, exo-, macro-, and chrono-system.

The **microsystem** refers to systems closest to the individual and directly in contact with the individual daily (Bronfenbrenner & Morris, 2006:817; Teater, 2021:50). The microsystem includes systems such as family, school, work, friends, peers, communities (Teater, 2021:50). In this study the microsystem will include the CWID, siblings, extended family, school of the CWID - Apricot Tree Centre in Benoni, professionals offering services to CWID, and the social system.

More recently various scholars have argued modifications in the ESP to include technology as an element within the microsystem of the ESP as it has become an integral part of daily living. Johnson & Puplampu (2008:4), proposed the addition of the **techno-subsystem** within the microsystem of children in the ESP. Navarro & Tudge (2023) propose a **neo-ecological theory** that presents a virtual and a physical microsystem within the ecosystem. The overarching premise of both theories argues that the ESP originates from before the introduction of screens and technology into daily living, the theory does not accommodate the significant influence of technology in the lives and ecosystems of children and adults (Johnson & Puplampu, 2008:4; Navarro & Tudge, 2023). Access to information and support through technology such as online forums, support groups and websites; the impact of technology engagement and societal world views communicated through technology, may impact the ecosystem of parents caring for CWID. This highlights the influential role of technology in ESP.

The **mesosystem** refers to interactions and relationships within the microsystem (Bronfenbrenner & Morris, 2006:817; Teater, 2021:50). Interactions within the microsystem impact the person and the quality of relationships within the microsystem (Teater, 2021:50). An example of the mesosystem in the ecosystem of a parent caring for a CWID can be the interaction between the CWID and their school. Hypothetically, the interaction, relationship quality, and the extent to which the school, namely Apricot Tree Centre, meets the child's developmental needs will impact the parent's relationship with the school and the stressors on the parent.

The **exosystem** refers to systems not directly involved with the individual's life, but that have an impact on the system through its decision-making and structure (Bronfenbrenner, 1979:47). For parents caring for CWID, this can include school policy, support services in the community, cost of living and employment conditions (Vadivelan, Sekar, Sruthi & Gopichandran, 2020:2).

The **macrosystem** includes larger systems that indirectly influence the individual's life, such as cultural norms, government legislation and policies, and global factors (Langer, 2014:33–34). In this study, social norms and values, South African policy and legislation regarding disability, and global views on disability are incorporated into this system of the parents' ecosystem (Vadivelan et al., 2020:2).

The **chronosystem** refers to age, phases of life, and life events that have impacted the system in any way (Bronfenbrenner, 1979:83). Eddy (2013b:142) is opined that changes in any system of a parent caring for a CWID, will ripple through all the layers, affecting large aspects of the parent's lives. Parents' varying responses to psychosocial factors (Graf, 2018:178) and the interaction with various systems throughout the CWID lifespan, are understood and interpreted through the chronosystem.

Below is a hypothesised schematic representation of the Ecosystems Model, adapted from Teater (2021:52) by the researcher, of factors that may play a role in the MH of parents caring for CWID in this study.

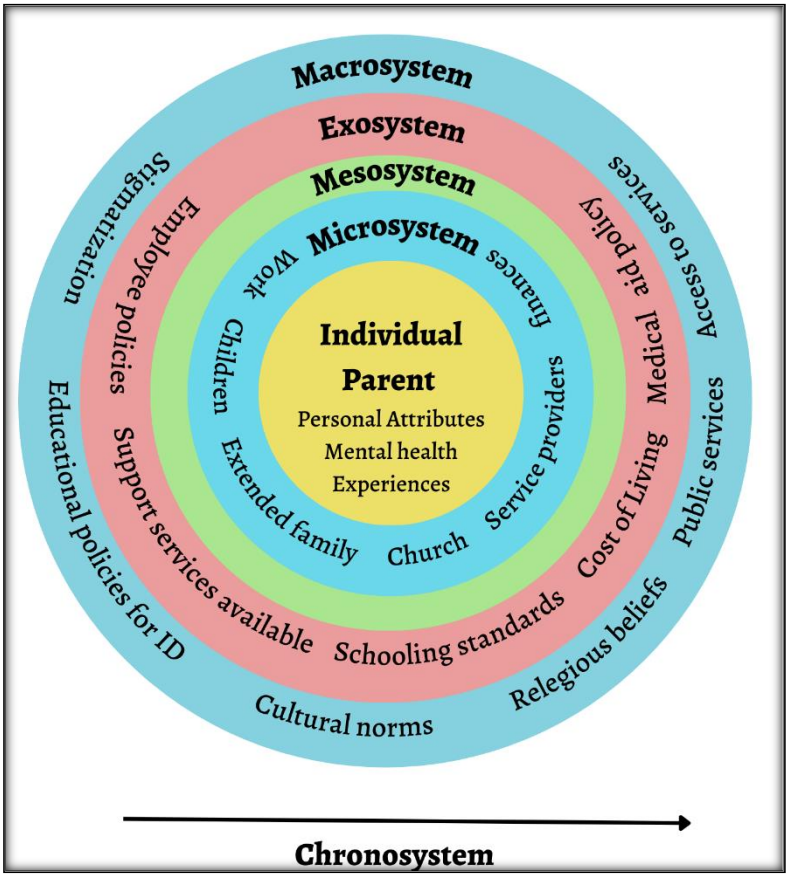

Figure 1.1 Tentative Ecosystems Model as hypothesised by the researcher for parents of children with intellectual disabilities [Adapted from Teater (2021:52)]

The above figure hypothesises that the parent and direct systems such as the CWID, other children, work, community, and church all represent the reality of the parent. The mesosystem indicates the interaction between the individual and its microsystem, with external factors such as cost of living, support services, access to services, stigmatisation and beliefs and norms. This guideline changed and evolved as the researcher explored the phenomenon. The researcher aimed to interpret and meaningfully understand the factors impacting the MH of parents caring for CWID by viewing information through the ESP.

The ESP allowed the researcher to understand and make sense of the phenomenon within the participant's unique environment, social setting, values, and culture, which allowed for a decolonised understanding of the participant's reality (Mbedzi, 2019:100). The risk presented is that the researcher over-analyses the ecosystem of the participant, to the point of skewing the data (Teater, 2021:35). Awareness of this risk assisted in mitigating the risk of skewed data.

1.3 PROBLEM STATEMENT AND RATIONALE

After consulting literature on various international and domestic research databases (University of Pretoria library database, Google Scholar, EscoHost, Google, WHO, Studies by UNICEF, Sabinet) and literature (Chauke, Poggenpoel, Myburgh & Ntshingila, 2021; Hanson, 2013; McKenzie, Abrahams, Adnams & Kleintjes, 2019; Mmangaliso & Lupuwana, 2021; Olusanya, Kancherla, Shaheen, Ogbo & Davis, 2022), it was evident that limited research is available regarding psychosocial factors impacting parents caring for CWID within the South African context. A lacuna exists in understanding these parents' experience of psychosocial factors affecting their MH, within the unique social and environmental South African context.

The rationale for conducting this study was that the findings can guide social workers in better supporting parents of CWID. The findings of this study would be able to further guide the development of targeted services for these parents, ultimately improving their MH. Lastly, the research can be used to compare the findings of similar research studies in South Africa, to increase understanding of psychosocial factors affecting the MH of parents caring for CWID.

This study aimed to answer the following research question:

> **What are the psychosocial factors affecting the mental health of parents caring for children with ID in Benoni, Gauteng?**

1.4 GOALS AND OBJECTIVES

The goal of the study was to explore the psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng. The study had the following objectives:

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

- To suggest recommendations for improving the services provided to parents caring for children with intellectual disabilities.

1.5 RESEARCH METHODOLOGY OVERVIEW

The research purpose of the study was exploratory. The researcher explored the participants' experiences and reality concerning factors affecting their MH to gain insight into the research question (Fouché, 2021a:65). The research paradigm for this study was interpretivism, as it explored the reality parents' subjective interpretation of their reality based on their own individual views, culture, experiences and values, rather than exploring reality as an absolute truth (Engel & Schutt, 2016:64).

A qualitative study allowed the researcher to gain an in-depth understanding of the phenomenon of caring for CWID rather than aiming to obtain quantifiable information (Fouché, 2021b:42).

The research type for this study was applied research. The findings of this study can assist social workers in practice to understand the psychosocial factors affecting the MH of parents caring for CWID, and in turn, assist social workers to tailor practical services in the immediate future (Adler & Clark, 2015:360). An instrumental case study was deemed most appropriate for this research (Creswell, 2013:107). An instrumental case study allowed the researcher to explore the phenomenon (case) of psychosocial factors affecting the MH of these parents, by gaining insight into the individual, and personal experiences of the parents (Creswell, 2013:109; Nieuwenhuis, 2020d:90). The narrow aim of the study set out in the goals and objectives of the proposed study served as boundaries and parameters needed for rigorous research (Nieuwenhuis, 2020d:90). An instrumental case study as a research design allowed the researcher to study the phenomenon within the context without compromising the quality of the study (Yin, 2018:50). The focus of the study was the phenomenon of psychosocial factors affecting the MH of participants, and not the participants themselves.

The study population were English- and Afrikaans-speaking parents caring for CWID at Apricot Tree Centre in Benoni, Gauteng. Most of the families using their services are generally middle-income families. The majority of children attending this centre have severe to profound ID and are unable to benefit from school-based programs. Six participants were recruited through non-probability purposive sampling. Purposive sampling was determined as the most suitable for this study as participants were

selected with a specific purpose in mind, according to the predetermined criteria set out (Rubin & Babbie, 2016b:446).

Face-to-face semi-structured interviews as a data collection method allowed the researcher to develop a foundation of open-ended questions based on literature while allowing the researcher flexibility in asking follow-up questions that emerge from the information provided by the participant (Geyer, 2021:358). This allowed for in-depth data collection on the parents' personal experience of factors affecting their MH, allowing them to communicate what is important to them (DeCarlo, 2018:365).

Data was analysed through reflexive thematic analysis (RTA). RTA resulted in the analysis of patterns and themes within the research data, that answered the research question (Braun & Clarke, 2022:5). Data quality was ensured through credibility, transferability, confirmability and dependability and the applicable ethical considerations were addressed.

A detailed description of the research methodology and methods follows in Chapter 3.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

Parenting children with intellectual disabilities (CWID) holds unique challenges and opportunities for parents and caregivers. Understanding these challenges and experiences within the South African context is essential for improving service delivery to parents of CWID. Although parents caring for CWID face numerous obstacles, this review rejects the sole 'tragic view' on caring for CWID by balancing challenges and resilience. (Minnes, Perry & Weiss, 2015:557). The South African context offers various socioeconomic settings impacting access to services for parents of CWID. Diverse socioeconomic settings, combined with cultural diversity, require a broad and culturally informed literature analysis. Understanding the different challenges in different settings is essential to improve service delivery to parents of CWID. Benoni, where this study was conducted, will inform this chapter, with its multicultural, middle-class context.

2.2 CONTEXTUALISING INTELLECTUAL DISABILITY

Understanding ID within the historical context leading to the current prevailing views within society and science, are important foundational knowledge to understand the context of ID. This section further explores the nature, diagnosis, prevalence, and cooccurring conditions and challenges of ID.

2.2.1 Historical developments in understanding intellectual disability

From the earliest recorded history, ID was associated with a decreased value of life (Roth, Sarawgi & Fodstad, 2019:3). Brown, Wehmeyer and Radford (2017a:19) highlight that ID is a social construct that changes meaning and understanding with time and place, influencing our understanding of ID throughout history.

As with all history regarding the early history of the antiquity age, information is scarce and lacking, making it difficult to understand the prevalence and perceptions of ID in that period. (Brown et al., 2017a:21). Archaeological and pictorial history, however confirms the presence of ID and connects the condition with spirituality (Brown et al., 2017a:21). During the Middle Ages, ID was surrounded by superstitious and religious theories, curses, demons, witchcraft and punishment for sins (Nehring & Lindsey,

2016:33–34; Roth et al., 2019:4). Although medical science moved away from this notion in the 18th and 19th centuries, as the understanding of the causes of ID emerged, some societies still hold on to such notions (Nehring & Lindsey, 2016:33–34; Roth et al., 2019:4).

The Industrial Revolution period brought a major shift in society as a whole by assigning greater personal value to the productivity of a person; emphasising differences in ability; and separating the abled from the disabled (Brown et al., 2017a:24). This mindset increased medical understanding and emphasis on social reform and paved the way to the era of institutionalisation of persons that are differently abled (Brown et al., 2017a:26). Although institutionalisation of persons with ID attempted to address social reform for society and care for differently abled, it greatly contributed to the mindset that differently-abled persons should be set apart from society. The era of institutionalisation of ID persons was driven by a desire for more humane treatment, asylums, or institutions for persons, but neglect and abuse continued. Up until the 1950s, most persons with moderate to severe ID were living removed from society in some or other forms of institution (Roth et al., 2019:9). 'Normal' society played little role in the lives of persons with ID, and parents with CWID did not play an active role in their daily care.

Since the 1950s until now, mental health (MH) has gone through a process of deinstitutionalising the care of persons with ID, placing them back into communities (Nehring & Lindsey, 2016:37–39). Advocacy for deinstitutionalisation was more often than not driven by parents and activists in the community rather than professionals working in the sphere of disability (Brown et al., 2017a:30). Bengt Nirje, an activist in deinstitutionalisation trends, emphasised that with the advances made in medicine, disabilities cannot be the sole identification or classification factor for the person (Brown et al., 2017a:31). The environment in which a person lives has a far more significant impact than the disability, emphasising the importance of integrating persons with ID into social environments where there is potential to develop and thrive (Brown et al., 2017a:31). Today, society is becoming more inclusive of persons with ID, placing the responsibility of care back on the parents (McKenzie et al., 2019:206).

The history depicted above is true for most of the Western, developed world and White South Africans, but for indigenous South Africans the history of ID looks quite different (McKenzie et al., 2019:204–205). Early recorded history relates ID to spiritual forces, curses, and supernatural abilities (McKenzie et al., 2019:205). Some traditional cultures

within South Africa still hold to these beliefs. During the 1800s and early 1900s, asylums generally hosted mentally ill and intellectually disabled patients together without distinguishing a difference in diagnosis or treatment (McKenzie et al., 2019:205).

During Apartheid, black, coloured, and Indian citizens did not have access to institutionalised care for persons with ID or special education as White South Africans were prioritised in health care (McKenzie et al., 2019:205). It is important to refrain from assigning Western history to all South Africans but rather be informed about the various cultures' beliefs and understanding of ID. At the inception of a democratic South Africa, the constitution and other policies took deliberate action to eliminate discrimination against persons with ID and aim to create inclusive environments (McKenzie et al., 2019:206).

This shift to deinstitutionalisation has been commendable on paper. Still, the reality of policy and resource management has led to several tragedies (McKenzie et al., 2019:207). The Life Esidimeni tragedy in South Africa, caused major mistrust in the government's ability to make responsible choices and care for persons with ID, and associated facilities (McKenzie et al., 2019:208). Pervasive ableism in society and service delivery hamper the authentic shift to inclusion (Capri, Abrahams, McKenzie, Mkabile, Saptouw, Hooper, Smith, Adnams, Swartz & Ockert Coetzee, 2018:11). Families in South Africa often bear the sole responsibility for caring for CWID, and lack access to basic support services (McKenzie et al., 2019:207). The Department of Social Development provide grants for persons with disability; however, grants are not nearly enough to cover the cost of caring for someone with ID and are often an entire family's primary source of income (McKenzie et al., 2019:206).

2.2.2 Policy and legislation in South Africa

South Africa does not have legislation purely focused on disability. The Mental Health Care Act 17 of 2002 (Republic of South Africa, 2002), and the Schools Act 84 of 1996 (Republic of South Africa, 1996), provide the most fundamental aspects of legislation for persons with disabilities.

The abovementioned legislation, together with the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016) set out the rights and services for persons with disability. The culmination of these documents advocates for equal rights in services, education, opportunity, and human rights for persons with

disabilities. The Schools Act 84 of 1996 (Republic of South Africa, 1996) advocates for inclusive education that enhances the quality of life for persons with disabilities and addresses learning barriers.

The South Africa legislation and policies align with the United Nations (UN) (2024) Sustainable Development Goals (SDG), such as SDG 3 which promotes good health and well-being and SDG 10 which strives to address inequalities in all areas of life.

However, Engelbrecht, Nel, Smit & Van Deventer (2016:2) acknowledge the challenges in the implementation of these policies to be effective change agents in South Africa. Some of the challenges include over emphasis on the medical model, stigma and beliefs within communities, and lack of resources (Engelbrecht et al., 2016:2-3).

2.2.3 Models of disability

Various models of disability exist to inform approaches, views and interventions regarding disabilities. Although these models compass all areas of disabilities, they will be discussed within the context of ID. The classic approach to disability is typically the medical model. The medical model views disability as an individual problem that requires a cure or treatment so that the individual can function in society (Goering, 2015:134; Haegele & Hodge, 2016:195). This model focuses on the individual's ability to fit the norms of society rather than society's willingness to be inclusive and depart from the perception of 'normal' (Haegele & Hodge, 2016:195). Although the medical model has significantly contributed to scientific developments in the treatment and prevention of disabilities, it fails to assign value to persons with disability outside of their impairments. Once all treatment options are exhausted, persons with ID may feel that their limitations are not the most significant limitations in their lives but rather society's response to their limitations (Goering, 2015:134).

Capri et al. (2018:2) postulate that the social model of disability separates impairment from disability. An individual may have an impairment as discussed under diagnostic criteria, "but their political and social environments do the disabling" (Capri et al., 2018:2). The person's diagnosed impairment is viewed as a functional limitation, while "disability is therefore viewed as a socially produced injustice" (Lawson & Beckett, 2021:348). The social model of disability emphasises the lack of society's willingness to accommodate a person's impairment, which is the disabling factor (Young & Berry, 2016:2). The social model of disability is criticised for making the individual an inactive

spectator to their own fate, placing all the onus on society (Capri et al., 2018:2). The criticism mentioned above invites a third model of disability.

The WHO provides a more integrative bio-psychosocial model of disability (Capri et al., 2018:2). The International Classification of Functioning, Disability and Health (ICF) describe disability and complex interaction between the person's health conditions, in the instance ID, and context (Federici, Bracalenti, Meloni & Luciano, 2017:1). The ICF better upholds the active role persons with disabilities play in their own lives while incorporating the political and social roles in inclusion (Federici et al., 2017:2). The ICT aligns with social work values and the principle of self-determination, acknowledging the right and desire for a person to make their own decision (Banks, 2021:78), while upholding social justice in challenging discrimination and promoting equality for persons with ID (Banks, 2021:98–99).

2.2.4 Definition and diagnosis of intellectual disability

Throughout history, persons with ID were often referred to as feebleminded, imbeciles, morons or idiots (Brown, Wehmeyer & Shogren, 2017b:4; Cervantes et al., 2019:46). Such terms failed to define ID and the diagnostic criteria clearly, relying heavily on subjective perspectives (Cervantes et al., 2019:46). The abovementioned terms are now associated with derogatory perceptions about persons with ID. Currently, the DSM-5-TR (American Psychiatric Association [APA], 2022:38) indicates three diagnostic criteria for ID: Deficits in intellectual functions (1) and adaptive functions (2), and onset before the age of 18 years (3). Intellectual functioning refers to a person's ability to learn, process, reason, exercise judgement, engage in academic learning, problem-solve, and make decisions (APA, 2022:39; Tejakum, Tankumpuan, Suksatan, Saboonma, Phetrasuwan & Rodney, 2022:361). Adaptive functioning refers to aspects of independence, the ability to perform tasks of daily living, appropriate communication and social functioning (APA, 2022:339). IQ measures are no longer a diagnostic criterion for ID, as greater focus is placed on adaptive functioning as a better indicator of support needed (APA, 2022:42). The DSM-5-TR cautions that diagnosis, treatment, and understanding of ID must be sensitive to cultural perceptions of functioning, causes and beliefs (APA, 2022:45).

ID are classified and diagnosed into four categories: mild, moderate, severe and profound (APA, 2022:39). A significant change between the DSM-IV and DSM-5 is that

IQ scores are no longer central to the classification system. Instead, the focus has shifted toward assessing an individual's functional abilities. Persons with mild and moderate ID can live and function independently with varying degrees of support and assistance (National Academies of Sciences, Engineering, and Medicine, 2015:170). Patel et al. (2016:7) emphasise that while mild ID will require intermittent support and moderate ID will need consistent support, both are viewed as time-limiting support requirements in the long term. A person with severe ID will require life-long support with significantly limited independence across the lifespan (National Academies of Sciences, 2015:171; Patel et al., 2016:7). Lastly, children with profound ID will require intense, around-the-clock care throughout their life span in all aspects of their lives (APA, 2022:39; Patel et al., 2016:7).

Although the current diagnostic criteria in the DSM-5-TR project are acceptance, support and inclusivity focused, an understanding of the history of ID highlights the actual landscape of parenting a CWID.

2.2.5 Prevalence of intellectual disability

ID is a worldwide phenomenon, but determining prevalence is difficult. A global disability prevalence study by Global Research on Developmental Disabilities Collaborators (GRDDC) estimates disability as a whole in persons under 19 between 10% and 11.4% of the population group (Olusanya et al., 2022:1). This study analysed data from the United Nations Children's Fund (UNICEF) Disability Report 2022 and the Global Burden of Diseases study in 2019. Global ID prevalence is estimated between 3–4% (Olusanya et al., 2022). The GRDDC (Olusanya et al., 2022:1) report that disabilities as a whole are significantly more prevalent in developing parts of the world, such as South-East Asia and Sub-Sahara Africa. Recent South Africa Census 2022 results indicate that 3.3% of the population experience difficulty remembering and concentrating (Statistics South Africa [StatsSA], 2023:62). These results are in line with global findings but lack definitive accuracy as they are not based on diagnosis but rather on personal experience. The subjective nature of the diagnosis, lack of consensus regarding terminology (McKenzie et al., 2019:204), and lack of comprehensive healthcare access impact the empirical validity of statistics. However, these findings are still deemed valuable in understanding the prevalence (Capri et al., 2018:3). The subjective interpretation of ID is further profoundly entrenched in a historical understanding of ID.

2.2.6 Causes of intellectual disability

ID aetiologies can be genetic, prenatal, perinatal postnatal, or acquired in childhood (APA, 2022:45). ID broad risk factors can be categorised as non-preventable and preventable. In developed countries, ID is most often caused by non-preventable factors. However, in developing countries, including South Africa, mal-nutrition, infectious disease, environmental factors, poor prenatal care, poor maternal healthcare, and social factors are major preventable risk factors that contribute to the prevalence of ID in Africa (Rubin, 2016:583–585).

Percy, Brown and Fung (2017:176) argue that risk factors are a more appropriate term than causes. Causes imply that one factor can cause ID, whereas researchers believe it is instead a combination of risk factors that usually cause ID. Furthermore, the aetiology in mild and moderate ID is often unclear or non-identifiable (Cervantes et al., 2019:48).

Non-preventable risk factors represent factors such as genetics, birth abnormalities, and non-preventable disease (Patel et al., 2016:7). Leonard, Montgomery, Wolff, Strumpher, Masi, Woolfenden, Williams, Eapen, Finlay-Jones, Whitehouse, Symons, Licari, Varcin, Alvares, Evans, Downs and Glasson (2022:2) states that “Genetic risk factors include a broad range of chromosomal abnormalities, autosomal trisomy’s, aneuploidies of the X-chromosome, and pathogenic”. It will be beyond the scope of this review to discuss all genetic risk factors of ID, but it is important to note that Down Syndrome is the most prominent ID related to genetic factors (Percy et al., 2017:180).

Preventable risk factors are broad and varied but often relate to poor socioeconomic environments. Environmental factors refer to factors that impact a person’s development and existence (Graff & Foran, 2016:348). Exposure to environmental toxins during prenatal and early childhood developmental stages has been linked to ID (Graff & Foran, 2016:349). These toxins include lead, mercury, insecticides, pollution, and alcohol and illicit drug exposure (Graff & Foran, 2016). Of these, alcohol is the most common toxin causing ID (Lee, Cascella & Marwaha, 2023). It is clear that factors such as alcohol and illicit drug exposure are linked to social problems within communities and are more prevalent among lower socioeconomic communities. Poor control and policies in developing countries play a major role in environmental factors contributing to ID (Patel et al., 2016:7).

Poor maternal care, including poor nutrition; uncontrolled diseases such as diabetes and HIV; postnatal care such as HIV, infection and nutrition in babies; and prevention of maternal diseases such as Rubella, are all preventable risk factors (Lee et al., 2023; Leonard et al., 2022:2). The nature of these preventable causes can all be addressed through access to quality health care and health education, emphasising the preventative nature of these risk factors. (Rubin, 2016:584). Understanding preventable risk factors highlights the higher prevalence of ID in developing countries. Developing countries are estimated to account for 85% of the ID population globally (Masulani-Mwale et al., 2016:871).

In South Africa, the risk of ID is compounded by the country's quadrupled burden of disease (Republic of South Africa, 2012:331). Various authors support these findings by arguing that tuberculosis, HIV/Aids, high prevalence of infectious diseases, high mother and child mortality rate, alcohol abuse and accidents and injuries increase the risks of ID in South Africa (Capri et al., 2018:3; McKenzie et al., 2019:205; Rubin, 2016:584). This argument proposes that South Africa's ID prevalence should be higher than reported, although statistics do not reflect this.

2.2.7 Comorbidities and cooccurring conditions of intellectual disability

Comorbidity refers to more than one illness or disorder in an individual (APA, 2024a) and often refers to the secondary conditions surrounding a primary disorder (Matson, 2019:121). ID is often a result of other conditions and diseases such as genetic disorders, HIV and TB, and cerebral palsy (CP) (APA, 2022:46). At the same time, CWID are more likely to develop certain conditions such as autism, ADHD, mood disorder, epilepsy and sleep disorders (Mori, Downs, Wong, Heyworth & Leonard, 2018:1652). The burden of care for CWID is often augmented due to comorbidities that present with ID. Comorbid conditions can significantly impact the quality of life, parental challenges, treatment options, complexity of care, and financial implications of care (Matson, 2019:121–124). Understanding comorbidities is essential to ensure optimised care and treatment for CWID (Flanigan, Climie, Gray & Conde, 2019:923). Lack of understanding of comorbidities can hamper access to adequate treatment and support for their child. Two prominent comorbidities are epilepsy and sleep disturbances.

Epilepsy is the most common comorbidity for ID and can often hold a high mortality rate if diagnosed with ID (Alvarez, 2016:936). The underestimation of epilepsy in CWID can

lead to a misunderstanding of the medical care needs of the child. Robertson, Hatton, Emerson and Baines (2015:59) report that 30–40% of children with severe to profound ID have epilepsy as a comorbidity. Epilepsy significantly increases the burden of care on caregivers, correlating with caregiver/parental distress. (Torres, Arca-Cabradilla, Sy, Corrales-Joson, Moral-Valencia & de Sagun, 2019:333).

Sleep disturbances are a prevalent comorbidity with ID (Didden, Braam, Maas, Smits, Sturmey, Sigafoos & Curfs, 2014:219). Sleep disturbances impact both the child and the parent as lack of sleep causes irritability and behavioural problems during the day for the child, and fatigue and low tolerance in caregivers (Didden et al., 2014:220).

Comorbidities in CWID complicate the well-being of the child and the parent. In conclusion, comorbidities add to parental distress and caregiver burnout, impacting the MH of parents caring for CWID.

2.2.8 Behavioural challenges in children with intellectual disabilities

CWID often have behavioural challenges. While many families with a child who has ID demonstrate resilience and adapt well, behavioural challenges can lead to poorer outcomes for these families (McConnell, Savage & Breitkreuz, 2014:1). Behavioural challenges disrupt family equilibrium and relationships, limit the family's ability to engage in social environments, challenge the safety of family members and cause emotional stress (Mazzucchelli et al., 2019:744; McConnell et al., 2014:1).

Staunton et al. (2020:5) argue a bidirectional aspect between behavioural challenges and parental well-being, finding that parental distress directly correlates to distress and behavioural difficulties in CWID. Behavioural challenges in CWID complicate the parents' ability to fulfil their parental roles. McConnell et al. (2014:11) argue that this relationship is far more complicated than other factors, such as social support and financial stability, which play a significant role in the relationship between parental distress and behavioural challenges. However, it is clear from the literature that behavioural challenges add substantial additional pressure to parental well-being and parents' ability to cope with the challenges of caring for a CWID. (McConnell et al., 2014:11; Staunton et al., 2020:5). This again emphasises the interconnected nature of parental well-being, characteristics of the child and external factors such as access to support and resources.

2.3 PARENTING AS A GLOBAL PHENOMENON

A brief overview of parenting as a whole is required to comprehensively understand the factors impacting parents caring for CWID. Parenting is a universal phenomenon which can cause great hardships while also being extremely rewarding.

The Children's Act of South Africa (Republic of South Africa, 2006:39) focuses on parental rights and responsibilities including caring for a child, maintaining contact with the child, acting as a guardian to the child, and supporting the child financially. However, this understanding of parenting only touches on the most concrete parenting factors. Understanding the true nature of parenting is better set out by the American Psychological Association. According to APA (2024b):

> *"Parenting practices around the world share three major goals: ensuring children's health and safety, preparing children for life as productive adults, and transmitting cultural values."*

The APA provides a holistic framework that underpins parenting in various social, economic and cultural contexts.

In South Africa, parenting challenges are experienced due to vast cultural and economic discrepancies. Poor housing and sanitation, child-headed households, high rates of teenage pregnancies and urbanisation (Roman, 2014:214–215) challenge parents to meet parenting goals. Roman (2014:216) refers to cultural diversity in South Africa as a factor that propels parents to emphasise the transmission of cultural values, acting as a protective factor to parenting within the South African context. However, recent shifts towards individualism and autonomy threaten the transmission of cultural values and parental satisfaction (Roman, 2014:216).

All three parenting goals mentioned by APA (2024b) above, are often threatened by single-parent households, with absent fathers, implicating lower educational levels in mothers and dire financial situations in families in South Africa (Roman, 2014:22). Parents in developing countries such as South Africa are often unable to progress past physiological and safety needs, as depicted by Maslow (Trivedi & Mehta, 2019:39). In contrast, middle-class families in suburban settings such as Benoni, are often not faced with these challenges to the same extent. However, across the board in South Africa, parents experience stress regarding ensuring productive lives for their children as adults, as the economic situation and unemployment are a stark reality for the majority of parents.

2.3.1 Implications of parenting children with an intellectual disability

Parenting a CWID makes the already complex task of parenting even more complex. Returning to the global goals set out by the APA above, parents caring for CWID experience challenges in firstly ensuring children's health and safety, (APA, 2024b) as the health of CWID are constantly threatened by health challenges. Secondly, preparing children for life as productive adults (APA, 2024b) is not always possible, as children with moderate to profound ID often remain dependent on parental care throughout their lifespan. Lastly, parents caring for CWID are not always able to transmit cultural values (APA, 2024b), due to the limited cognitive and adaptive functioning of persons with ID.

Despite these challenges, parents simultaneously report benefits in caring for CWID (Masulani-Mwale et al., 2016:872; Mazzucchelli et al., 2019:743). The personal growth that parents experience in caring for a CWID is viewed as a benefit for many parents (Mazzucchelli et al., 2019:743). Like parenting children who appropriately meet all their milestones and adjustments, many parents of CWID report positive effects as a result of parenting, contributing to the parent's MH and quality of life (Kimura & Yamazaki, 2019:218). These positive effects include having a greater appreciation for life and more meaningful relationships, together with a sense of accomplishment (Kimura & Yamazaki, 2019:218). Parents caring for CWID also identify beneficial factors such as self-growth, tolerance, and deepening spirituality, as part of caring for CWID (Masulani-Mwale et al., 2016:872).

2.4 MENTAL HEALTH OF PARENTS

Mental health (MH) is not the exclusion of mental disorders but the ability to cope and adapt to challenges in life, to form and maintain healthy relationships, and the ability to be productive members of society (APA, 2022; WHO, 2022). Contrary to the general belief, the absence of MH does not imply mental illness, but rather a state of mental ill health or MH demotion (Bhugra, Till & Sartorius, 2013:3).

When a parent has good MH, they will experience a positive sense of self, assisting them in forming positive relationships across the board (Bhugra et al., 2013:4). These parents will have resilience that enables them to cope with challenges and respond positively to challenges they face in day-to-day and in parenting a CWID (WHO, 2022). Lastly, parents with MH can positively contribute to their community, family and society

(WHO, 2022). It is essential to understand what MH is in order to assess the research question accurately.

Various internal and external factors can influence a person's MH. Internal factors will include aspects such as self-esteem, emotional resilience, and isolation (Bhugra et al., 2013:3). External factors include factors such as socioeconomic conditions, discrimination, poverty, cultural conflict and stigma, connecting MH and psychosocial factors (Bhugra et al., 2013:3).

2.4.1 Mental health and psychosocial factors intersecting

The APA (2024a) definition of psychosocial factors seems most appropriate at the intersection of psychological, social, environmental and cultural influences on the mind and behaviour. In the context of psychosocial factors impacting the MH of parents caring for CWID, MH cannot be understood outside the social, environmental, and cultural aspects of parenting a CWID.

Returning to the definition of MH and psychosocial factors discussed above, the research question of this study is essentially asking: What psychosocial factors strengthen, support, or threaten a parent's ability to cope and adapt to challenges, form healthy relationships, and contribute to society?

2.5 PSYCHOSOCIAL FACTORS

Various factors such as social support, stigmatisation, severity of disease, own health, financial situation, anxiety, depression, family dynamics, public policy, cultural values and spirituality all intersect to ultimately affect the mental well-being of parents caring for CWID (APA, 2022:876; APA, 2024a; Islam et al., 2022:216; Masulani-Mwale et al., 2016; Staunton et al., 2020:1). It is essential to acknowledge that all psychosocial factors can be a risk factor or a protective factor for parents caring for CWID. This review aims to gain insight and understanding of psychosocial factors and their role in the MH of parents caring for CWID. According to the systems theory, every psychosocial factor is interrelated and interconnected and should be viewed as such. Psychological factors, social support, cultural and religious contexts, stigmatisation, socioeconomic factors, access to services, and caregiver burnout will be discussed as psychosocial factors impacting the MH of parents caring for CWID.

2.5.1 Psychological aspects

The psychological factors such as anxiety and depression, as well as identity and self-image are focussed on as psychosocial factors affecting the MH of parents caring for CWID.

2.5.1.1 Anxiety and depression

Caring for a CWID is associated with a range of emotions. Parents describe these emotions as ranging from experiencing the diagnosis as the most traumatic event in their life to feelings of thankfulness and clarity on the meaning of life (Tarbox, Garcia & Clair, 2016:231). Initial reactions to diagnosis include shock, denial, and disbelief (Graf, 2018:178; Isa, Ishak, Ab Rahman, Mohd Saat, Che Din, Lubis & Mohd Ismail, 2016:72). As parents come to terms with the diagnosis, parents may feel overwhelmed, confused, and profoundly sad (Graf, 2018:178). They might also grapple with guilt, blaming themselves for their child's condition, which can lead to depression and feelings of helplessness (Graf, 2018:178). Parents often compare receiving an ID diagnosis for a child with the grief of losing a loved one. Parents may mourn the loss of the life they had envisioned for their child and have to adjust their expectations accordingly (Graf, 2018:179). Depending on the nature of the disability, parents may need to adjust their physical, emotional, and cognitive expectations, which can evoke feelings of anger or self-blame (Graf, 2018:178).

Unfortunately, the range of emotions experienced, combined with challenges in caring for a CWID, often lead to adverse emotional responses which affect the parents' decision-making ability, and MH (Graf, 2018:178). These emotional responses place parents at risk of developing anxiety and depression, correlating with Islam et al. (2022:216) findings that parents caring for CWID are more likely to suffer from depression and anxiety. Shahali, Tavousi, Sadighi, Kermani and Rostami (2024:9) found that psychological distress can be so severe that it leads to suicide or suicide idealisation.

Depression is described by feelings of hopelessness, sadness, emptiness, and lack of motivation that interfere with eating, sleeping and daily life (APA, 2024a; Islam et al., 2022:212). Anxiety is an emotional response characterised by apprehension, stress, tension and related physiological responses that are future-orientated (APA, 2024a). A firm link exists between the severity of ID, parental stress and quality of life (Staunton

et al., 2020:5). Other studies suggest that lack of social support, disruptive sleep patterns, behavioural problems, grief-related feelings due to diagnosis, lack of respite, and financial pressure are contributing factors to depression and anxiety in these parents (Dunn, Kinnear, Jahoda & McConnachie, 2019:7; Masulani-Mwale et al., 2016:875; Mazzucchelli et al., 2019:744). Differing views on contributing factors confirm the complex nature of this phenomenon. Parents' anxiety is often centred around the future care of their child, financial stressors, care needs and well-being of the child (Isa et al., 2016:73).

Parental roles play an important role in a parent's experience of anxiety and depression. Dunn et al. (2019:7) postulate that fathers of CWID tend to experience less depression and anxiety. This finding may have less to do with gender characteristics and more with the traditional gender roles still assumed today. Fathers are more likely to play the role of the breadwinner outside of the house, thus assuming less responsibility for the care of a CWID, in turn resulting in lower levels of anxiety and depression (Dunn et al., 2019:7). Ultimately Dunn et al. (2019:7) argue that employment outside the home serves as a protective factor against anxiety and depression for all parents of CWID. The reality of this phenomenon in the South African context, where many parents earn minimum wage and are under enormous financial pressure, has not been explored. Masulani-Mwale et al. (2016:876) confirm this finding in the African context, where women traditionally shoulder the majority of the childcare burden.

In a study by Tejakum et al. (2022:365), depression is indicated as the primary predictor of resilience in caregivers of CWID. Depression places parents at risk of low resilience when caring for CWID. Various psychosocial factors discussed below underpin anxiety and depression in parents caring for CWID and increase their vulnerability to MH problems.

2.5.1.2 Identity and self-image

Caring for CWID, especially children with severe to profound ID, can be an all-consuming task for parents, reaching into every part of their life shaping how they think about themselves and the world (Cantwell, Muldoon & Gallagher, 2015:949). Core beliefs refer to a person's fundamental beliefs regarding themselves and the world (Wearden, 2008:1247). It can be concluded that caring for a CWID impacts a parent's core beliefs about themselves and the world. The negative narrative in society, that

having a CWID is tragic and seen as a punishment, can affect a parent's sense of self, facilitate self-stigmatisation, and negative self-beliefs (Cantwell et al., 2015:949; Hastings, 2016:189).

Cantwell et al. (2015:949) report that factors such as problem behaviour or profound disability increase a parent's perception of negative social encounters, social hostility and social stigmatisation. Perceived stigmatisation impacts a parent's perception of self and self-esteem (Cantwell et al., 2015:955). This can fundamentally shape a parent's core beliefs and identity.

Self-esteem is an essential element in predicting the quality of life of parents caring for CWID, with self-efficacy as a protective factor and low self-esteem as a risk factor for poor quality of life (Isa et al., 2016:75).

2.5.2 Family

The discussion of the family will include changes and adjustments within families, family dynamics and marital relationships.

> *"Disability, like a rock thrown in a pond, has repercussions that reverberate throughout the elements and routine of the family's life." (Hanson, 2013:101).*

As parents and children are in a constant dynamic relationship, it is pertinent to understand the various factors that influence the distress and well-being experienced by families with CWID. Type of disability, behavioural problems, gender and cultural roles within the family, socioeconomic status, access to services, spirituality, caregiver burden, and coping skills within the family play a role in the family's ability to cope with the challenges (Eddy, 2013a:165; Hanson, 2013:101; Power & Dell Orto, 2004:71-75). In line with most literature, the focus here will be on the nuclear family, while the extended family forms part of the social support context.

2.5.2.1 Changes and adjustment within families

Changes within the family system, such as relationship, well-being and role changes, are inevitable when caring for a child with an ID is included (Lima-Rodríguez, 2018:91). However, the belief that caring for a CWID has a solely negative impact on the family is slanted and may be overlooking families that have found a way to develop family cohesion and well-being (Hastings, 2016:188).

Graf (2018:177) identifies three types of families that determine how well individuals adjust to disabilities: balanced-, midrange-, and extreme families. The balanced family, considered most resilient, exhibits rhythm and regenerativity, whereas extreme families display low adaptation and high dysfunctional patterns. Rhythm represents the family's ability to establish routines and rules that promote closeness and understanding among family members, leading to flexibility and satisfaction (Graf, 2018:177). Regenerativity refers to family coherence and resilience, including care, respect, loyalty, and shared values. It is normal for families to initially and sporadically experience disequilibrium and dysfunction in coming to terms with ID and its implications. However, ultimately, a balanced family manage to make meaning out of their experience of ID, develop healthy coping mechanisms, and establish a family environment where all members can thrive (Graf, 2018:177).

2.5.2.2 Family dynamics

Family dynamics significantly impact a parent's experience of having a CWID. Kimura and Yamazaki (2019:226–228) study found that mothers with more than one child have better MH and quality of life compared to mothers with only one child, despite experiencing greater financial stress. However, the decision to have more children is often influenced by fear of having another CWID (Kimura & Yamazaki, 2019:226).

Masulani-Mwale et al. (2016:872) argues that togetherness and cohesion in families can be a factor that contributes to the resilience of parents caring for CWID. A greater sense of purpose and greater sense of collective achievement and togetherness were experiences identified in families (Hanson, 2013:101). Furthermore, as much as family cohesion is viewed as a protective factor for parents caring for CWID, marital discord and stress are highly reported among parents of CWID (Graf, 2018:173).

2.5.2.3 Marital relationship

Similar to parents, marriage alone is a challenging endeavour. Combining marital challenges with caring for CWID result in tremendous stress on marital relationships. Graf (2018:174) argues that caregiving burden, leisure activities limitations, unequal task division and financial burdens are major contributors to marital discord (Graf, 2018:174). However, marital support can play an essential role in creating a positive outlook on life and caregiving responsibilities for parents caring for CWID (Beighton & Wills, 2019:1271).

Tarbox et al. (2016:231) found that 23% of parents caring for CWID, had marriages that end in divorce, compared to 13% of parents without CWID. Various studies have found that factors such as chronic stress and behavioural problems of CWID play a role in marital discord (Graf, 2018:173; McConnell & Savage, 2015:101).

Despite the challenges faced by families, family cohesion is an essential protective factor for the MH of parents caring for CWID (Hanson, 2013:101). Sharing caregiver burden and emotional support from a spouse facilitates a positive outlook for the primary caregiver and leads to long-term resilience (Beighton & Wills, 2019:1271). Family support for families with ID should focus on building capacity and strengthening the family to ensure the best possible care and support for CWID and overall resilience and MH for all family members (Reynolds, Gotto, Agosta, Arnold & Fay, 2016:7).

2.5.3 Social support

Social support is a double-edged sword for the MH of parents caring for ID, as it can both be a protective and risk factor for the parents (Hanson, 2013:98). Parents of CWID often have the greatest need for social support. Still, the challenges of caring for their child disrupt social relationships significantly (Masulani-Mwale et al., 2016:872). Kimura and Yamazaki (2019:218) refer to social support as social capital and define it as “the degree of connectedness and the quality and quantity of social relationships”. Social support can be formal or informal structures. Not only do friendship and informal social relationships assist in practical support, but social relationships and friendships also impact the parents’ perception of emotional well-being (Boehm & Carter, 2019:110).

Healthy, positive social support can be a protective factor, as it assists parents in coping with challenges and functioning better in society (Hanson, 2013:5). Poor MH outcomes for parents caring for CWID are buffered by social support, indicating higher resilience levels in parents (Tejakum et al., 2022:366). Informal social support within the family and community can reduce MH problems for parents, reduce marital strain and increase coping and quality of life of parents (Halstead, Stanley & Greer, 2019:333). However, social support is subjective in nature and is dependent on the parents’ perception thereof (Halstead et al., 2019:333). Halstead et al. (2019:333) and Marini (2018b:300) argue that the presence of various forms of support, such as practical, emotional, and educative support, creates a perception in parents that they receive adequate social support.

Negative social support, such as dysfunctional support, or the absence of support can place a parent and child at risk of maladaptive coping mechanisms and the formation of dysfunctional family systems (Masulani-Mwale et al., 2016:877). This includes instances where social support systems may pressure parents into making harmful decisions for their CWID, such as neglect, abandonment, or even filicide (Masulani-Mwale et al., 2016:877). Other negative social support may encourage dysfunctional coping mechanisms such as substance abuse or risky behaviour (Marini, 2018a:300). Often, the lack of social support is driven by the challenges parents experience in social engagement due to stigmatisation or demands of caregiving (Shahali et al., 2024:9). Lack of social support is a predictive factor in low resilience (Tejakum et al., 2022:366).

Within South African communities, poor understanding of ID and its causes and stigma regarding ID, decreases social support and leads to parents, especially mothers, experiencing isolation within communities (Malatji & Ndebele, 2018:139). Some authors argue that greater informal social support exists in South African communities as communities are accustomed to the lack of formal support (Rubin, 2016:585), while other authors argue that cultural views on disability and stigmatisation decrease social support in African communities (Masulani-Mwale et al., 2016:872).

2.5.4 Spirituality and cultural aspects

Hanson (2013:98) maintains that the cultural and community context in which the parents live plays a vital role in their ability to cope with their parenting challenges. Interconnectedness in community, culture, clan, spirituality and the individual play an important role in understanding African communities, culture, spirituality and family (Kpanake, 2018:198). Most African cultural beliefs regarding disability are interconnected with spiritual beliefs (Hanson, 2013:98). For this reason, it will be discussed as interconnected, while we acknowledge that Western views have a less interconnected nature between culture and spirituality.

The culture of Ubuntu has been a strength in African cultures for generations. Kpanake (2018:201) describes Ubuntu as: “African values of collective relatedness, interdependence, communality, group solidarity, and conformity.” Despite the strength of Ubuntu, in the spirit of Ubuntu, communities may be ill-equipped to deal with individuals who do not conform to the norm, such as persons with ID (Hailey, 2008:18). The commonality of Ubuntu dictates that ‘out-of-the-norm’ features such as illness and

disability be interpreted in terms of ancestors and spirituality (Kpanake, 2018:207). This is supported by Masulani-Mwale et al. (2016:874), finding that cultural values in Africa are often non-supportive to parents caring for CWID, coercing them into neglect, femicide or traditional interventions to address the 'disorder'. The nature of ID and the prevalence of seizures within the disorder are often interpreted within communities as the presence of evil spirits or demons (Masulani-Mwale et al., 2016:874).

Spirituality and religious views are found to be both a source of strength and a source of stigmatisation for parents of CWID. For centuries, myths and spiritual beliefs have blamed disabilities on spiritual aspects. With variations in cultures and time periods, disabled people have been blamed for being bewitched, demon-possessed or cursed. Even though societies in developed countries have eradicated the notions to a large extent, some societies in developing countries like South Africa, still hold to this notion (Rubin, 2016:585). These beliefs regarding ID, lead to increased stigmatisation experienced by CWID and their parents, directly contributing to isolation and a reduction in social support (Masulani-Mwale et al., 2016:876).

Contrastingly, spiritual beliefs can play an essential part in parents' ability to cope and find meaning in their circumstances (Boehm & Carter, 2019:111). Spirituality can help parents process the fact that their child has an ID and adjust their viewpoint to see the child as a blessing and accept the disability (Masulani-Mwale et al., 2016:872, 876). Furthermore, religious communities can be a source of support for parents of CWID (Masulani-Mwale et al., 2016:876).

2.5.5 Stigmatisation

Stigmatisation is present in all societies across various spectrums, including illness and disability. Scior (2016:5) highlights three crucial aspects of stigmatisation: Firstly, stigmatisation is a process of labelling and stereotyping a person or their behaviours. Secondly, stigmatisation involves a process of negatively affecting a person's normal identity, and thirdly, it involves an element of one party being superior and exercising power while the other party are labelled inferior. This understanding confirms that stigma is firmly rooted in societal beliefs that a person's value is attached to the contribution they can make to their community (Scior, 2016:6) and moral principles.

Although great strides have been made in reducing stigma in society towards disability, in all societies, there are still firmly held stigmatised beliefs about persons with ID (Scior,

2016:6). As society is shifting from valuing cognitive strength above physical strength, stigmatisation of physical disabilities is reducing while disabilities affecting cognitive functioning remain stigmatised (Scior, 2016:6).

As for moral drivers of stigmatisation, misconceptions about the causes of ID, such as punishment from God, sins of the fathers, ancestral elements, actions of the parents, demon possession and witchcraft, contribute to the stigmatisation of persons with ID (Rohwerder, 2018:4). Subsequently, African culture is still deeply entrenched with beliefs that ID has a spiritual connection, making cultural stigmatisation very real and loaded for parents in South Africa (Masulani-Mwale et al., 2016:876).

Stigmatisation negatively affects families caring for CWID by impacting their access to education, health, employment and community connectedness (Ditchman, Kosyluk, Lee & Jones, 2016:32–37). This, in turn, leads to lower social support in the community; even family distance them from persons with ID, leaving much of the burden of care solely on the parent (Chauke et al., 2021:6). Hastings (2016:189) and Cantwell et al. (2015:949) link stigmatisation to poor self-image and identity discrepancies in parents caring for CWID. The negative attitudes and stigma regarding ID make parents caring for CWID vulnerable to isolation and poor MH outcomes (Cantwell et al., 2015:948).

2.5.6 Access to services

South Africa has made significant progress in providing equal access to services for all citizens, yet vulnerable groups continue to face barriers in access services across various sectors (Mkabile & Swartz, 2020:1). Capri et al. (2018:9–11) found that CWID lack access to health care, legal rights and justice, transport, and rehabilitation services. Mkabile and Swartz (2020:1) distinguish structural barriers and mental barriers as factors that lead to a lack of access to services for CWID. Structural barriers include physical factors such as cost, transportation, facility inaccessibility, and lack of services, while mental barriers refer to individuals' choice not to use available services. Whether systemic barriers or by choice, lack of access to services continues to impact the health outcomes of CWID (Mkabile & Swartz, 2020:2) and the MH of the parents.

Although the South African Bill of Rights and the White Paper on the Rights of Persons with Disabilities clearly state that all children, irrespective of their disability, have a right to education, the minority of CWID attend school (Capri et al., 2018:5–6). Although

policies are inclusive and empowering, the lack of prioritisation and implementation of policy, hamper services on community level (McKenzie et al., 2019:205).

Mkabile and Swartz (2020:3) explored the reasons why South African parents who had access to services chose not to use them:

> *"Common themes identified included financial difficulties, fragile care networks and opportunity costs, community stigma, lack of safety, lack of faith in services and powerlessness at effecting changes, self-stigmatisation, feelings of incompetence and guilt."*

Lack of access to services is not only limited to CWID. Most programs that include parent training are focused in higher-income countries, with few such programs available to parents in lower-income countries (Susanty, Noel, Sabeh & Jahoda, 2021:422).

As South Africa's service delivery becomes more politically motivated and embattled in corruption (Thusi & Selepe, 2023:695), the lack of public services, care support, and educational services are contributing factors affecting the MH of parents caring for CWID (Mmangaliso & Lupuwana, 2021:14). Lower-income parents who are motivated to improve the quality of life for their child find that due to their economic situation and the public service delivery, access to quality services for a CWID is limited and hard to access, leading to feelings of hopelessness, frustration, and anxiety (Mmangaliso & Lupuwana, 2021:14).

2.5.7 Caregiving burden

A caregiver is responsible for the daily needs, medical needs, and developmental needs of a child (Arora, Goodall, Viney, Einfeld & the MHYPEDD team, 2020:104). Within the South African context, most of the caregiving burden of CWID falls upon the parents, due to the lack of educational programmes for CWID (Capri et al., 2018). Caring for a CWID has mental and physical implications. Parents directly involved in the caregiving of CWID are more likely to experience fatigue, poor health outcomes, stress and isolation (Arora et al., 2020:103; Masulani-Mwale et al., 2016:872). Lifting and physically caring for teen and adult CWID pose physical challenges for parents. Studies have found a link between caregiving responsibilities and poor physical health outcomes for parents (Masefield, Prady, Sheldon, Small, Jarvis & Pickett, 2020:569), making them more susceptible to stress-related conditions and chronic illness.

The severity of disability, behavioural problems and comorbid conditions significantly influence the caregiver burden, as more intensive, specialised and ongoing care is needed for children with more severe forms of disability (Arora et al., 2020:106; Staunton et al., 2020:1). Specialised knowledge of caring for medical conditions is required, and often parents do not feel that they are competent carers, affecting the confidence in caring, self-image, anxiety of parents and the well-being of the child (Burd, Burd, Klug, Kerbeshian & Popova, 2019:125).

Parenting often gets lost in the chaos and challenges of caregiving. As caregiving continually trumps parenting needs and stressors escalate within the caregiver, the parents' ability to fulfil their parental role diminishes, leading to poorer outcomes for long-term relationships within the family (Peer & Hillman, 2014:93).

Caregivers often experience emotional and physical exhaustion as their caring responsibility never ends (Mmangaliso & Lupuwana, 2021:15). Hypervigilance and being in constant 'care mode' can lead to caregivers feeling isolated and disconnected from society (Griffith & Hastings, 2014:416). This places caregivers at risk of caregiver burnout.

2.5.7.1 Burnout in caregivers

Parents caring for children with mild to moderate ID are at lower risk of burnout, while parents caring for children with more severe ID are at higher risk of burnout (Sadziak, Wilinski & Wieczorek, 2019:77). Caregiver burnout can be detrimental for the caregiver, child and family and pose significant risks, while respite and alternatives for caregiving, are not always possible for families.

Lima-Rodríguez (2018:94) mention factors that contribute to caregiver burnout to include: the continuous care demands, caregiving challenges, and work-care burden. The ever-present demand of caregiving, combined with behavioural challenges, significantly impacts the MH of caregivers (Griffith & Hastings, 2014:416). Considering that 10–20% of CWID present with behavioural challenges (Griffith & Hastings, 2014:416) behavioural problems should be acknowledged as a factor contributing to burnout.

Understanding the challenges of caregiving helps shape services for parents caring for CWID, and although very few view the caregiving role as wholly fulfilling, parents take up this critical role to ensure the best possible care for their children (Griffith & Hastings,

2014:416). Exploring factors that protect parents against burnout and exhaustion will significantly impact the well-being of the parent, child and family.

2.6 RESILIENCE IN PARENTS CARING FOR CHILDREN WITH INTELLECTUAL DISABILITY

Many studies argue the important role of resilience in parents caring for CWID. Resilience is defined as “the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioural flexibility and adjustment to external and internal demands” (APA, 2024a). The ecocultural theory regarding resilience is constructive in understanding the various factors in play to bring about a resilient family in the face of challenges. The ecocultural theory argues that in order for families to thrive, the family have to find a way of living that is predictable, stable, congruent with their values and beliefs, and fitting within their social and cultural contexts (McConnell et al., 2014:3). From the ecosystems perspective, various internal and external factors are associated with resilience in caring for CWID.

Despite challenges experienced by parents of CWID, literature provides us with insight into the resilience within this community that results in better-than-expected outcomes in MH. Various studies have aimed to answer the question as to the reason that some families cope better than expected, while other families develop significant dysfunction. Although many of these studies differ in the findings, positive reframing and optimism, formal and informal support as factors, and religion contributing to play a significant role in the parent’s ability to overcome the challenges of caring for CWID (Chauke et al., 2021:7; McConnell et al., 2014:11; Peer & Hillman, 2014:94–95). Isa et al. (2016:75) agree that cognitive reframing, acceptance, optimism and religious support are positive coping mechanisms that decrease parental distress, while reiterating that task-orientated coping styles are linked to increased parental distress. Peer and Hillman (2014:94) assert two main coping styles making internal and external adjustments to goals and expectations or strategies to regulate emotions. The one style is not necessarily better than the other, only different. Understanding the factors contributing to resilience will be instrumental in improving social work services for these parents.

2.6.1 Reframing and reasonable hope

Minnes et al. (2015:552, 557), identify that parents' ability to reframe their child's disability and their circumstances as a positive coping mechanism in coping with the challenges of caring for a CWID. By restructuring core beliefs and negative assumptions, parents create positive perceptions regarding their child and their circumstances that assist in resilience (Minnes et al., 2015:552). Such a process of reframing creates hope, better termed reasonable hope. Although the term reasonable hope is mainly used within cancer psychosocial intervention, it can be applicable to use within understanding parents' ability to create hope within their child's diagnosis. Weingarten (2022:11) defines reasonable hope as:

> *"Reasonable hope directs our attention to what is within reach more than what may be desired but unattainable."*

Once reframing and adjustment have taken place, a reasonable hope can be built, leading to a better quality of life, greater positive regard and the opportunity to "make meaning of one's life" (Boehm & Carter, 2019:110). Hope for positive change and better-than-expected outcomes are viewed as an essential factor in resilience building and a decisive predictive factor of the MH of parents of CWID (Kimura & Yamazaki, 2019:228).

2.6.2 The role of support in resilience

Social support, family support and professional support are found to impact a family's resilience and ability to cope with the challenges of caring for a CWID. McConnell et al. (2014:11) argue that the negative impact of behavioural challenges does not compare to the positive impact of robust social support. However, the negative impact of behavioural challenges on social support is underestimated (Mazzucchelli et al., 2019:744).

Both informal and formal support play an important role in the resilience of parents caring for CWID (Boehm & Carter, 2019:100). Informal structures of support, specifically families, are a natural resource and buffer to parents caring for CWID against poor MH outcomes (Boehm & Carter, 2019:99).

The view that having a CWID is a tragic event is rejected by most parents caring for CWID (Minnes et al., 2015:557). Parents find that positive aspects of caring for a CWID do exist. Parents report that they value their personal growth, the sense of achievement from caring for their child, and the development of deeper spiritual connection as

positive aspects (Beighton & Wills, 2019:1273). A different outlook on life that fosters gratitude and tolerance is seen as personal gains for parents caring for CWID (Beighton & Wills, 2019:1273). The abovementioned positive aspects of caring for a CWID illustrate the function and value of positive reframing in resilience.

2.7 SUPPORT AND INTERVENTION FOR PARENTS CARING FOR CHILDREN WITH INTELLECTUAL DISABILITY

Growing evidence suggests that parental and child well-being are closely related (Hatton & Emerson, 2015:23). This challenges the traditional approach of focusing services for CWID on the children. The lack of support services for parents in South Africa are a risk factor for poor MH outcomes (Kromberg, Zwane, Manga, Venter, Rosen & Christianson, 2008:93). Holistic services will facilitate better outcomes for the family and child (Minnes et al., 2015:557). Services for CWID and their parents, require a multidisciplinary approach, as ID is not purely a medical phenomenon or a purely social phenomenon (Hewitt, Esler, Stronach, Zemanek, Adler, Arndt, Cassidy, Peyton & Rich, 2016:2111). Ideally, services that address psychosocial factors affecting parents should be delivered concurrently with services to CWID (Masulani-Mwale et al., 2016:871).

The complex nature of the caring requirements of CWID requires support and intervention from a wide range of professionals such as dietitians, occupational therapists, physiotherapists, psychologists, speech and language therapists, audiologists, remedial therapists and social workers (Hewitt et al., 2016:2111–2122). The abovementioned professionals assist persons with ID and their families to live meaningful and integrated lives in society, aiming to promote optimal quality of life for people with ID and their families (Hewitt et al., 2016:2112). It will be beyond the scope of this literature review to look at each profession. Instead, the focus will be on support and intervention provided by social workers to CWID and their families.

Awareness of services for parents caring for CWID has been steadily growing in developing countries (Masulani-Mwale, Kauye, Gladstone & Mathanga, 2019:2). Unfortunately, specialised services for CWID are scarce in South Africa (Capri et al., 2018:2). Other studies in the rest of Africa also report the lack of access to services for CWID, as well as the lack of MH and support services for parents caring for CWID (Masulani-Mwale et al., 2016:876). (Masulani-Mwale et al., 2019:10) identify that services to parents need to be culturally sensitive and address the needs of the parents

such as respite care, psychosocial support and psychoeducation regarding diagnosis and care. A report on the Life Esidimeni tragedy, shows a vast disconnect between service policy, service delivery and community involvement regarding services for persons with ID (McKenzie et al., 2019:207).

2.7.1 Role of social work and services

Social workers can play a vital role in providing services, support, and intervention for parents caring for CWID. Social work services will be discussed as in terms of direct and indirect social work services.

2.7.1.1 Direct social work services

Direct social work services refer to services aimed at the patient or client, in this case the CWID and their family (Cowles, 2012:31). Social workers are involved in services for parents caring for CWID as case managers, counsellors, and educators. Central to case management for parents of CWID is addressing barriers to care, planning services and long-term goals for patients and families, and liaising with team members (Hewitt et al., 2016:2119). As case managers, social workers are essential in communicating information to parents and assisting them in decision-making (Hewitt et al., 2016:2119). Social workers can also act as counsellors for parents caring for CWID by supporting, counselling and assisting parents to navigate caring for their child (Hewitt et al., 2016:2119). With limited resources, group counselling and the facilitation of support groups are effective methods to create collaborative and accessible services (Masulani-Mwale et al., 2016: 877). Social workers play an integral role in services that focus on providing coping tools for parents caring for CWID to allow for better MH outcomes (Minnes et al., 2015:558). Social work services and support to families and parents of CWID cannot be limited to crisis intervention, but should rather focus on offering skills services across the life span, ensuring optimal well-being of the parent and the child (Masulani-Mwale et al., 2016:877).

2.7.1.2 Indirect social work services

Indirect social work services refer to the role social work plays on a community level that will indirectly impact the well-being of the parent caring for CWID (Cowles, 2012:38). Social workers, as advocates, can connect families to services and resources and advocate for the goals and rights of families (Hewitt et al., 2016:2119). Linking

parents with services can impact their access to services that in turn indirectly impact the functioning and well-being of parents. Advocating for access to services and equal rights on community and policy level will create inclusive communities that will benefit parents caring for CWID (Hewitt et al., 2016:2119). Together with this, social workers can act as educators in addressing stigma and myths within communities to cultivate more inclusive communities (Masulani-Mwale et al., 2016:877).

2.7.1.3 Social work values and principles

Core values of social work such as non-judgemental attitude, self-determination, social justice and empowerment play an important role in services for CWID and their parents. Social workers in practice should challenge and critically evaluate their views of disability and seek to understand the family's view on disability when working with families (Boehm & Carter, 2019:110). Social workers can address stigma in the profession and wider community by adopting a non-judgemental attitude and prioritising social justice. Focusing on a strengths perspective and the understanding of reasonable hope, social workers will be able to facilitate the development of positive coping strategies and resilience among parents caring for CWID (Boehm & Carter, 2019:110).

2.8 SUMMARY

The phenomenon of caring for a CWID is complex and challenging for parents. Professionals offering services to families caring for CWID will benefit from a better understanding of ID and the challenges associated with caring, protecting and nurturing a CWID. Knowledge of the causes of ID, the medical challenges of ID, and the role of comorbidities are essential to understanding the complexity of care. Various factors in a family's micro-, meso-, exo- and macrosystems impact the well-being of the child, parent and family. Understanding these factors is crucial in supporting parents in achieving optimal MH, directly impacting all family members.

The following chapter describes the research methodology and methods that were implemented during this study.

CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter comprehensively describes the research methodology used during this study, namely the research approach, type of research, research design and research methods. This includes the study population, sampling, sampling methods, methods of data collection and data analysis and pilot study. Lastly, the ethical considerations for this study are discussed.

3.2 RESEARCH APPROACH

The research paradigm for this study was interpretivism, which refers to the way a researcher's assumptions and beliefs about reality influence how the researcher approaches and interprets the data (Nieuwenhuis, 2020b:58). Interpretivism refers to the belief that an individual's reality or experience of reality is based on their subjective interpretations of individual views, culture, experiences and values, rather than believing that reality as an absolute truth (Engel & Schutt, 2016:64).

Using interpretivism as a paradigm, the researcher anticipated that the participants' experience of reality would inform the psychosocial factors affecting their MH (Nieuwenhuis, 2020b:58). The researcher does not focus on finding consensus, but rather exploring the various experiences of the participants (Rubin & Babbie, 2016b:63). Although the literature gave the researcher guidance on possible factors to consider and explore, the researcher did not assume to know which psychosocial factors affect the MH of parents caring for children with intellectual disabilities (CWID) in Benoni. Interpretivism acknowledges that each person's experience of psychosocial factors impacting their MH will be influenced by their own perception of reality. Their own experience of reality, in turn, is influenced by various factors in their ecosystem, past experiences, values, and cultural values, to name a few (Nieuwenhuis, 2020b:67). The participants' perceptions of psychosocial factors were paramount in answering the research question accurately. Interpretivism allowed for interpreting data in the study through either a Western or decolonial/Afro-sensed lens, depending on the cultural and social background of the participant, safeguarding against contextual misinterpretation.

This research was conducted using a qualitative approach. A qualitative approach supported the interpretivism paradigm, that there is no single truth regarding psychosocial factors affecting the MH of parents caring for CWID, supporting an inductive study to discover these factors (Rubin & Babbie, 2016b:63). Through the use of a qualitative study, the researcher was able to gain an in-depth understanding of the phenomenon of caring for CWID, rather than aiming to obtain quantifiable information (Fouché, 2021b:42). Furthermore, the qualitative design supports the ecosystems perspective as a theoretical framework, arguing that all persons are influenced by the interaction between the biological, relational, physical, environmental and social aspects of the individual's life (Teater, 2021:48). Combining qualitative research and the ecosystem perspective (ESP), allows for understanding the interaction between elements in each individual ecosystem rather than generalised assumptions.

3.3 TYPE OF RESEARCH

The research type for the study is applied research. This research can assist social workers within practice to understand psychosocial factors affecting the MH of parents caring for CWID and, in turn, assist them in tailoring practical services in the immediate future (Adler & Clark, 2015:360). The knowledge produced in this study can guide actions, programmes and practices used by social workers and other professionals working with parents of CWID (Fouché, 2021a:58).

The research purpose of the study was exploratory. The researcher explored the participants' experiences and reality concerning factors affecting their MH to gain insight into the research question (Fouché, 2021a:65). Although an exploratory study did not provide definitive answers on this phenomenon, the study is valuable in two aspects. Firstly, the findings provide a basis for knowledge for further studies (Babbie, 2017:92). Secondly, the findings can help social workers and other professionals working with parents of children with intellectual disabilities (ID) gain insight into the experiences of these parents, thereby informing the services provided to them (Babbie, 2021:91).

Applied research best aligns with the goals and objectives of this study as the objectives include recommendations on services to support parents caring for CWID.

3.4 RESEARCH DESIGN

A case study design was used for this research. Although the term case study often causes persons to draw the focus to the individual, in case study research, the phenomenon is the “bounded entity” or case rather than the participants (Nieuwenhuis, 2020d:90; Yin, 2018:50). Case study research refers to an in-depth study of a case or phenomenon within the context and reality in which it happens (Nieuwenhuis, 2020d:89). The case study design employed in this research proved remarkably effective, fostering collaboration between the researcher and participants and encouraging participants to share their stories openly. (Nieuwenhuis, 2020d:90).

As the research explores a specific issue or problem, an instrumental case study was most appropriate (Creswell, 2013:107). An instrumental case study allowed the researcher to explore the phenomenon (case) of psychosocial factors affecting the MH of parents caring for CWID in in-depth (Nieuwenhuis, 2020d:90).

When using instrumental case studies, the danger exists that in the process of identifying the ‘case’, the researcher selects a too wide a case to study (Creswell, 2013:109). The narrow aim set out in the goals and objectives of the study served as boundaries and parameters needed for rigorous research (Nieuwenhuis, 2020d:90).

3.5 RESEARCH METHODS

In this section, the researcher will lay out the research methods that were used for this study, addressing the study population, sampling approach, method and criteria, data collection, data analysis, data quality, and pilot study.

3.5.1 Study population and sampling

The study population for this study was English and Afrikaans-speaking parents caring for CWID at Apricot Tree Centre in Benoni, Gauteng. The Apricot Tree Centre is an NPO that runs a stimulation and development centre for persons with ID, ranging from 3–28 years of age. Although the organisation services a diverse population, the families using their services are generally middle-income families. The majority of children attending this centre had moderate to profound ID and were unable to benefit from school-based programs.

The sampling approach used for this study was non-probability sampling. The likelihood of an element of the sampling population to be selected as a participant for this study

was unknown as no random selection method was used (DeCarlo, 2018:271). Non-probability sampling excluded the possibility of generalising the findings of the study to the larger population, but allowed the researcher to draw a sample in line with the goal of this study (DeCarlo, 2018:271–272). Non-probability sampling enabled the researcher to collect rich, in-depth data regarding psychosocial factors affecting participants' MH (DeCarlo, 2018:271–272).

Purposive sampling was evaluated as the most suitable for this study. Participants were selected with the specific purpose in mind, according to the predetermined criteria set out below. Using purposive sampling allowed the researcher to select participants who were likely to provide the researcher with the most in-depth information to answer the research question (Rubin & Babbie, 2016b:446).

As Apricot Tree only has limited children under the age of 18, snowball sampling was used to obtain one additional participant. Snowball sampling refers to using a sampling method where the researcher has made contact with a suitable participant, in this case through purposive sampling, and then asks the participant to connect the researcher with other participants (Maree & Pietersen, 2020:220). Parents caring for CWID is a small interconnected community, making snowball sampling a valuable sampling approach (Babbie, 2021:193). One participant was identified by other participants, as her child was previously at Apricot Tree Centre.

For this study, Mrs Abby-Jade Reason, the centre's principal, acted as the participants' gatekeeper. The gatekeeper liaised between the researcher and the study population to make sure the privacy policy was respected. The gatekeeper made parents aware of the proposed study, using a participant information sheet and once parents were interested in participating, their contact information was forwarded to the researcher with their consent.

Through purposive and snowball sampling, the participants met the following inclusion criteria:

- Have to be parents of a child with an ID under the age of 18 years.
- Have to be Involved in the care and decision-making of a CWID.
- Have to be the parent of a child attending Apricot Tree Centre or benefiting from services offered by the Centre currently or in the past.
- Have to be able to communicate sufficiently in English or Afrikaans.

- Had to agree to participate in the study by completing the informed consent form.

The researcher used purposive and snowball sampling to recruit six participants for the study. The sample size was guided by information power.

Information power was used to determine the sample size. Malterud, Siersma and Guassora (2016:1754–1756) propose that data saturation is not the only way to determine sample size in qualitative studies, but that the following factors that impact the information power of the data have to be evaluated. Based on the information power model, the following components of this study indicate that a high level of information power can be attained through a relatively small sample size for the study (Malterud et al., 2016:1754–1756):

- Narrow goal: The study focused specifically on parents of CWID in Benoni, Gauteng.
- Dense specificity: Purposive sampling ensured that participants met all the inclusion criteria. The immersive experience of caring for a CWID offered rich and applicable data.
- Theory applied: The ESP as a theoretical framework assisted in interpreting the relationships between different elements of the data.
- Quality of the dialogue: Most participants interviewed were well articulated, emotionally aware and knowledgeable on the topic, allowing for extended data-rich interviews. The semi-structured interview schedule allows for report building between the researcher and participant, contributing to in-depth data on participant experiences.
- Data analysis strategy: Using reflexive thematic analysis in cross-case analysis requires a broader sample size, but the homogenous nature of the sample size mitigates this.

Borrowing from the data saturation method, after the 5th interview, the researcher felt that data saturation was reached, as no new information was surfacing but decided to conduct one more interview to confirm the absence of new themes. Data analysis confirmed the researcher's data saturation process as meaningful, well-defined and rich themes were generated Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, Burroughs and Jinks (2018:1899).

3.5.2 Data collection

Semi-structured interviews were used to collect the data for this study. This allowed the researcher to develop a foundation of open-ended questions from the literature on psychosocial factors affecting the MH of participants (Geyer, 2021:358), while remaining flexible for further exploration. Semi-structured interviews allowed the researcher flexibility in asking follow-up questions that emerged from the information provided by the participant (Geyer, 2021:358).

The semi-structured interviews benefited the study in facilitating the collection of in-depth data from the parent's personal experiences, allowing them to communicate what is important to them (DeCarlo, 2018:365). Semi-structured interviews allowed for the researcher and participant to build rapport, which plays an essential role in gaining in-depth data from the participant (Leedy et al., 2021:278).

A significant shortcoming of semi-structured interviews is that it demands much time from the researcher and participants (Geyer, 2021:358). The researcher believes that the value of information power of in-depth interviews with purposively selected participants superseded this disadvantage.

The researcher conducted one face-to-face interview with each participant at a location suitable for the participant and in the format the participant preferred. Two participants preferred to meet at Apricot Tree Centre, while one participant requested to meet at her house. Three participants preferred online meetings, as they had time constraints and work obligations that made in-person meetings difficult. Online interviews were conducted using Google Meet. Only the researcher and participant were present during the interview. With permission of the participants, interviews were recorded by means of a digital voice recording device and written notes by the researcher (Nieuwenhuis, 2020d:5). For data analysis purposes, the researcher personally transcribed the interviews using Microsoft Word and Turboscribe.

3.5.3 Data analysis

Data was analysed through reflexive thematic analysis (RTA). RTA is a flexible approach to data analysis that results in the analysis of patterns and themes within the research data (Braun & Clarke, 2022:5). The researcher acknowledges the reflexive/subjective nature of RTA as an element of data analysis by acknowledging the paradigm, theoretical framework, assumptions, and bias of the researcher that

influences the analysis of the data (Braun & Clarke, 2022:5). The reflexive nature of RTA allowed the researcher to acknowledge, adjust, and challenge their own biases, rather than ignore or deny the subjective aspects of data analysis. This approach ensured more reliable and accurate reporting of the findings. Inductive data analysis allowed for exploration of the factors constructing the reality of the parents, rather than measuring their experience to a pre-set framework (Schurink, Schurink & Fouché, 2021:403).

The data analysis process for this study is discussed in the following subsections.

3.5.3.1 Phase 1: Familiarising yourself with the data

The researcher immersed herself in the data, becoming deeply familiar with the data by listening to the interviews, transcribing the interviews and reading through the data multiple times, and identifying important elements (Braun & Clarke, 2022:35).

3.5.3.2 Phase 2: Coding

The researcher then slowly worked through the data during this phase, identifying relevant and meaningful elements and assigning codes. The coding process was flexible, organic and evolving throughout the coding process (Braun & Clarke, 2022:54–54). The researcher used the digital transcripts for ease of use, but manually assigned codes. Microsoft Word was used to assign codes and organise data. The researcher employed both semantic and latent levels of coding. For semantic coding the researcher focused on the explicit, surface-level information provided by participants, while during latent coding the researcher searched for underlying, implicit themes within the data. (Braun & Clarke, 2022:57). Particular focus was given to ensure the codes are clear and meaningful for accurate theme assignment during subsequent phases (Braun & Clarke, 2022:52). This was done by testing if the code is meaningful and independent on its own.

3.5.3.3 Phase 3: Generating initial themes

By identifying shared patterns across data sets and within the codes, the researcher generated themes related to the research question within the data (Braun & Clarke, 2022:35). Engel and Schutt (2016:408), are opined that a code captures an idea, whereas a theme captures a concept across codes, combining and grouping codes in a meaningful way. The reviewed literature as set out in the literature review, equipped

the researcher with an in-depth knowledge on the topic, but the inductive focus encouraged the researcher to remained flexible and adopt the themes that emerge from the data (Schurink et al., 2021:403). Participants experiences inform the findings, rather than the participant's experience confirming previous knowledge (Rubin & Babbie, 2016a:70). As themes were generated, ambiguous codes were reassessed and new codes generated and the researcher became more familiar with the data (Braun & Clarke, 2022:55).

3.5.3.4 Phase 4: Developing and reviewing themes

During this phase, the researcher reviewed the generated themes, ensuring that themes were meaningful in connection to the codes, data set, and research question (Braun & Clarke, 2022:35). Furthermore, codes were standardised across data sets within the specific themes, critically re-evaluating each code and theme for meaning and accuracy. Lastly, initial themes were reshuffled into logical patterns and clusters to ensure a meaningful presentation of findings (Braun & Clarke, 2022:97). Each theme was evaluated against the research question, making sure it contributes to exploring the question of what psychosocial factors affect the MH of parents caring for CWID.

3.5.3.5 Phase 5: Refining, defining, and naming themes

During this phase, the researcher strengthened the themes by clearly defining them, placing boundaries and making sure each theme is concisely described (Braun & Clarke, 2022:108, 111). Defining and refining themes allowed the researcher to execute final testing and organisation of the themes, ensuring that findings were presented in a systematic and logical manner (Braun & Clarke, 2022:108).

3.5.3.6 Phase 6: Writing up

The researcher wrote up the findings from the data analysis in a mini-dissertation format (Braun & Clarke, 2022:36). The researcher evaluated the data using the ESP to explore the factors affecting the participants' MH from an interpretivism paradigm. The theoretical framework, literature review, and data analysis collectively informed the development of this mini-dissertation's empirical findings and conclusion.

3.5.4 Data quality

Trustworthiness is measured by the credibility, transferability, dependability and confirmability of the data (Nieuwenhuis, 2020a:144–146). The trustworthiness of the study was ensured through the constructs discussed in the following subsections.

3.5.4.1 Credibility

Credibility refers to a study's accuracy in employing credible methodology and theoretical frameworks in conducting the study (Leedy et al., 2021:117). The credibility of the data was established through:

- Adoption of sound research methodology and design, as set out in this chapter (Nieuwenhuis, 2020a:144).
- The ESP framework provided a foundation for in-depth exploration of participants' personal experiences. This approach guided the researcher to recognise and appreciate the unique elements within each participant's ecosystem. The researcher analysed the data with the assistance of the ESP, as seen in Chapter 4.
- Member checks were used to allow participants to correct faulty findings in the study (Schurink et al., 2021:397). This was achieved by contacting participants afterwards to clarify data and collect additional outstanding data.

3.5.4.2 Transferability

The level to which the findings of a study can be applied to different situations and contexts are referred to as transferability (Schurink et al., 2021:393). This does not refer to generalisation of findings, but rather the effectiveness of the set parameters of a study, making the data valuable in similar situations (Nieuwenhuis, 2020a:144). The transferability of this study is ensure through clear communication of the following aspects throughout this dissertation:

- The in-depth nature of this study, thick description, and narrow goal, combined with purposive sampling for a clearly defined context, ensured the transferability of the data (Nieuwenhuis, 2020a:144–145).
- The context of the study is clearly defined to ensure clear boundaries on the transferability of the findings.

3.5.4.3 Confirmability

For a study to meet the criteria of conformability, the researcher needs to ensure that the findings are shaped by the experience of participants rather than the bias and preconceived ideas of the researcher (Leedy et al., 2021:269). Confirmability of this study was informed by:

- Maintaining awareness of the researcher's potential biases and exercising caution throughout the process (Nieuwenhuis, 2020a:145). In order to safeguard against the researcher's own bias, the researcher used rephrasing during interviews, to clarify what the participants meant and asked participants to clarify if the researcher understood the message the participants were communicating.
- Member checks used in conjunction with verbatim documentation within sufficient context confirm and clarify participants' intended meaning of statements (Nieuwenhuis, 2020a:147).

3.5.4.4 Dependability

Based on the credible research design of the study, dependability refers to the meticulous implementation and execution of the design, and the proof thereof (Nieuwenhuis, 2020a:145). Dependability was ensured by meticulous documentation of the research process and data analysis in a manner that can be reviewed and understood by independent parties (Nieuwenhuis, 2020a:145). This task reflects the true nature of the research process in relation to the research design (Nieuwenhuis, 2020a:145).

3.5.5 Pilot study

The pilot study is the process of testing the implementation of the planned study to address any challenges in execution and testing the effectiveness of the interview schedule (Strydom, 2021:386). Pilot pre-testing was conducted through one participant interview, to assess the clarity of the questions and the interview schedule's potential to provide the necessary data to answer the research question, allowing the researcher to adjust the interview schedule before data collection (Makofane & Shirindi, 2018:41). During this process, the estimated duration of the interview, recording devices, and logistical matters of the interview process was also tested. The pilot pre-testing

participant provided informed consent for the data to be used. As only minor changes were made to the interview schedule after pilot testing, the data from the pilot study was used in the primary research study.

Literature was consulted for the interpretation of the pilot study data in order to calibrate the interview schedule (Strydom, 2021:387). Similarly, consultation with experts and peers regarding the pilot study findings and required adjustments improved the feasibility of the study (Strydom, 2021:388). The pilot pre-test interview data was transcribed to get a transcription experience for the main study and was not included in the main study.

3.6 ETHICAL CONSIDERATIONS

The researcher considered the ethical implications and challenges of the study, understanding the responsibility and accountability required for ethical research practice (Mogorosi, 2018:75). The researcher strived to "protect human dignity and to promote justice, equality, truth and trust" during the study (Mogorosi, 2018:75). The researcher ensured ethical consideration and compliance in the following manner:

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria for the study (Appendix 3) (Nieuwenhuis, 2020c:48). Apricot Tree Centre provided written permission (Appendix 2) to conduct the study at the organisation, after being thoroughly informed on the scope of the study (Appendix 1). Furthermore, the researcher acted within the bounds of the code of conduct and code of ethics set out for social workers by the South African Council for Social Services Professions (South African Council for Social Services Professions, n.d).

3.6.1 Avoidance of harm and debriefing

The researcher was aware of the harm this study could cause to the participants. Although this study poses no physical harm, the researcher made cognisance of the possibility of psychological or emotional distress when discussing sensitive issues regarding parenting a CWID (Babbie, 2021:64–66). This risk of emotional harm was mitigated by debriefing participants at the end of the interview. Additionally, free counselling services were made available to all participants in need of support (Appendix 6). No participants indicated emotional distress or a need for counselling

services. All participants indicated that the interview was a positive and meaningful experience for them.

3.6.2 Informed consent

All participants were required to provide written and verbal informed consent to participate in the study after being made aware of the study by the gatekeeper initially, using the participant information sheet (Appendix 4), followed by the detailed full purpose of the study by the researcher using the letter of informed consent (Appendix 5) (Strydom & Roestenburg, 2021:122). Informed consent included consenting to the recording of the interview for accurate data collection purposes, data being used to inform the study and consent that data can be stored safely in a secure place for 10 years at the University of Pretoria and that the data collected could be used for secondary analysis in future research.

No participants were forced or coerced into taking part in the study, and voluntarily provided their contact details to the gatekeeper to give to the researcher to contact them. Participants were informed of the right to withdraw from the study at any stage (Babbie, 2021:63).

3.6.3 Gatekeepers

The role of gatekeepers was used and respected in the study to regulate access to participants and safeguard participants' rights (McFadyen & Rankin, 2016:82). Written permission was obtained from the organisation, as well as an agreement that Mrs Abby-Jade Reason of Apricot Tree Centre would act as a gatekeeper (Appendix 2). A participant information sheet was given to the gatekeeper to share with the potential participants and to provide her with their contact details should they be interested to participate in the study, which she subsequently was given permission to share with the researcher.

3.6.4 No deception of participants

The participants in the study were made aware of the nature, purpose and process of the study and what the intention was with the findings of the proposed study (Babbie, 2021:70). All relevant information was communicated to participants in the informed

consent and again at the start of the interview. The researcher will also share the findings with the participants and Apricot Tree Centre.

3.6.5 Privacy, anonymity, and confidentiality

While in-person interviews did not allow participants to remain anonymous to the researcher, all identifying details were kept confidential and were not accessible to unauthorised individuals or included in the research report. (Strydom & Roestenburg, 2021:124). Pseudonyms were assigned to each participant to protect their identity. Interviews were conducted in a private setting, ensuring the privacy of the participants (Strydom & Roestenburg, 2021:124). The interview was conducted solely by the researcher, removing the necessity for a non-disclosure agreement. Only the research supervisor had access to the transcribed data for supervision purposes. Anonymity could not be assured as the interviews were face-to-face.

3.7 SUMMARY

Sound, evidence-based research methodology was used in the planning and execution of this study with an aim to provide trustworthy findings that can contribute to social work practice in working with parents caring for CWID. The study was qualitative in nature, using in-depth one-on-one interviews to collect data regarding the personal experiences of parents caring for CWID. The data was analysed using reflexive thematic analysis, in order to answer the research question. Ethical practices preserving the dignity and safety of participants were paramount during this study.

The findings presented in Chapter 4 adhere to the process described in this research methodology chapter.

CHAPTER 4
RESEARCH FINDINGS

4.1 INTRODUCTION

This chapter focuses on the analysis and presentation of the empirical data. Empirical data for this study was collected through a series of semi-structured interviews of parents caring for children with intellectual disabilities (CWID). All participants are currently or were in the past affiliated with Apricot Tree Centre in Benoni, Gauteng. All participants care for children with severe to profound ID who will require intensive support and care across their lifespan.

Biographical findings are presented below in terms of the sample as a whole. Biographical data was acquired through closed-ended questions and information shared during the interviews. The biographical information is followed by a discussion of the themes and sub-themes obtained through RTA. Data analysis is supported by quotes from the participants and literature substrates these findings.

4.2 RESEARCH FINDINGS

The biographic findings and thematic analysis follow.

4.2.1 Biographical information

A participant profile of each participant was deemed as the most valuable manner in which to present participant details to sketch an image of the sample population. However, as all participants are affiliated with one organisation with a small population, and the findings of this study will be provided to the organisation, the biographical descriptions may have posed a risk of threatening the confidentiality of the participants. For this reason, biographical information is instead represented collectively of the sample of six participants. Biographical data are described in the context of the study and are limited to information that is of relevance to the study. Table 1 represents the biographical data of all participants interviewed. Pseudonyms are not included in this table, in order to protect the identity of participants. The data is also presented randomly to ensure the participants' confidentiality.

Table 4.1 Biographical information of participants

Age	Age of CWID	Occupation	Housing	Marital status	Disability	Caregivers	Medical aid
44	7	Professional nurse	Free-standing house	Married	Autism	No	Yes
42	8 +16	Administration	Townhouse	Married	Spata 5	Yes	Yes
n/a	15	Data Analyst	Free-Standing house	Married	Undiagnosed	No	Yes
32	4	Procurement Specialist	Flat	Divorced	Lissencephaly	Yes	Yes
46	17	Stay-at-home mom	Free-Standing house	Married	Chromosome 8 inversion	Yes	Yes
32	8	attendance analyst	Apartment	Married	ABI, CP, Epilepsy	No	Yes

It is clear from this table that the six participants interviewed, had a variety biographic circumstances and causes of ID. Further interpretations of the data are presented below.

4.2.1.1 Age

The ages of both the participants and their CWID are focused on here. Figure 4.2 presents the ages of the participants, while Figure 4.3 presents the age of the participants' CWID.

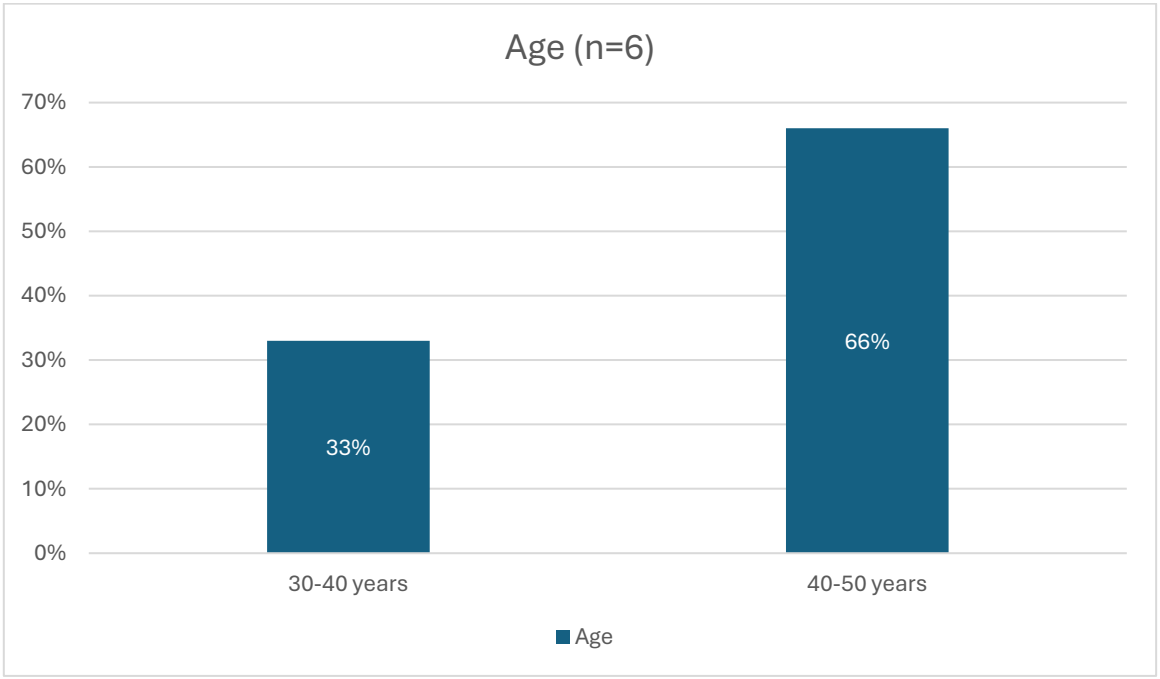

Figure 4.1 Ages of participants

Regarding the ages of the participants, 33% (2) of participants were between the ages of 30 and 40 years. The rest of the participants (4), 66% were between 40 and 50 years old. None of the participants fall outside the general childrearing age, with two participants indicating later-age pregnancies.

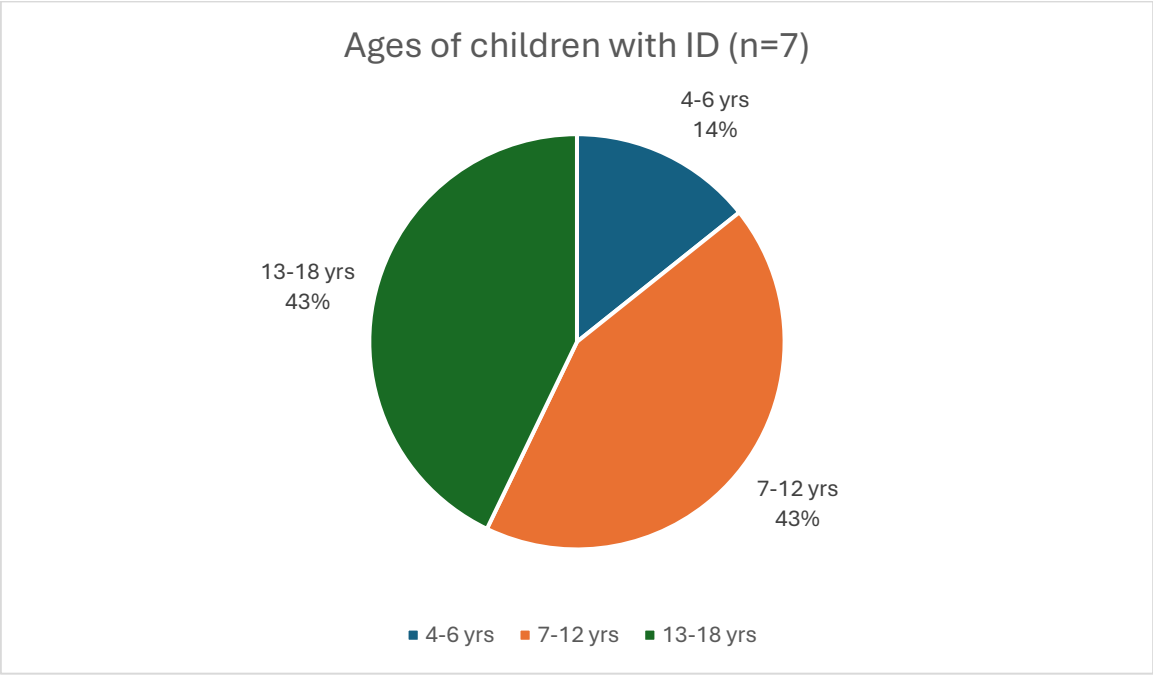

Figure 4.2 Age of children with ID

From this figure it is clear that the ages of the seven CWID, of the six participants varied. Three of these children (43%) were between the ages of 13–18 years, three (43%) children between the ages of 7–12 years and one child (14%) under the age of 6. All the children fall within the sample criteria of being under the age of 18 to accommodate the legal definition of children in South Africa (Republic of South Africa, 2006).

4.2.1.2 Family composition

This information is essential in understanding the family composition of the participants, affecting their challenges, protective factors and experiences. Table 4.4 presents the percentage of participants who have additional children that do not have an ID, while Table 4.5 indicates the marital status of participants.

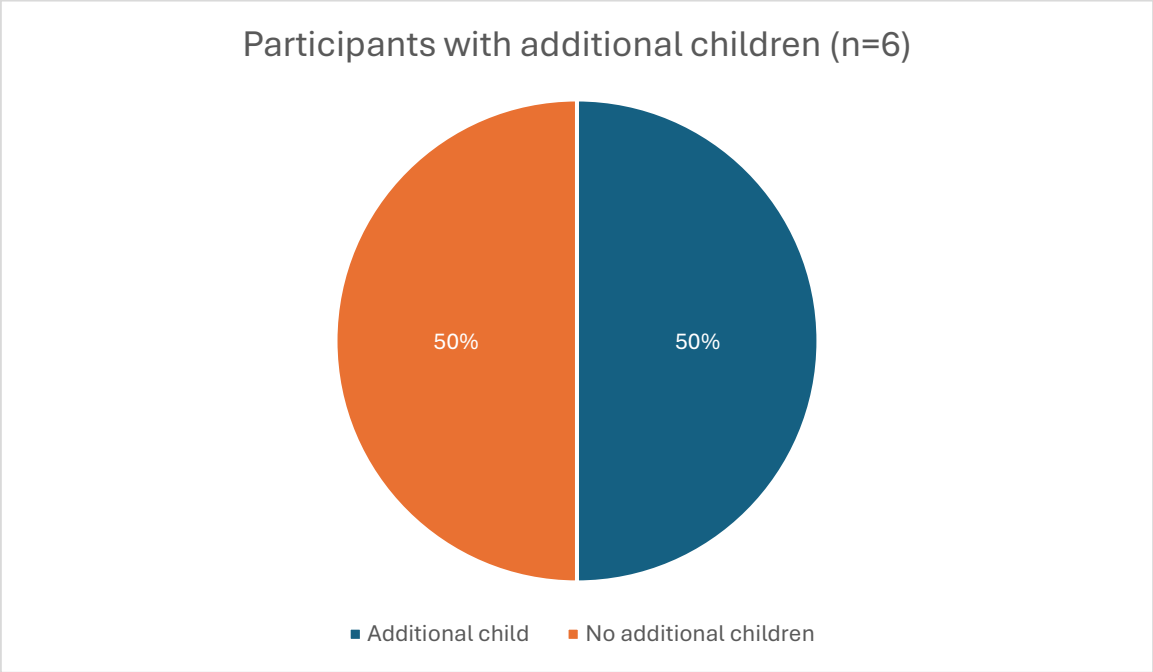

Figure 4.3 Participants with additional non-ID children

From the above figure, 50 % (3) of participants have additional children who do not have ID. However, only one participant (16%) has additional children that are younger than the CWID, while the rest of the additional children were older. This is in line with Kimura & Yamazaki (2019:226) finding that caring for a CWID significantly impacts the parent's decision to have more children.

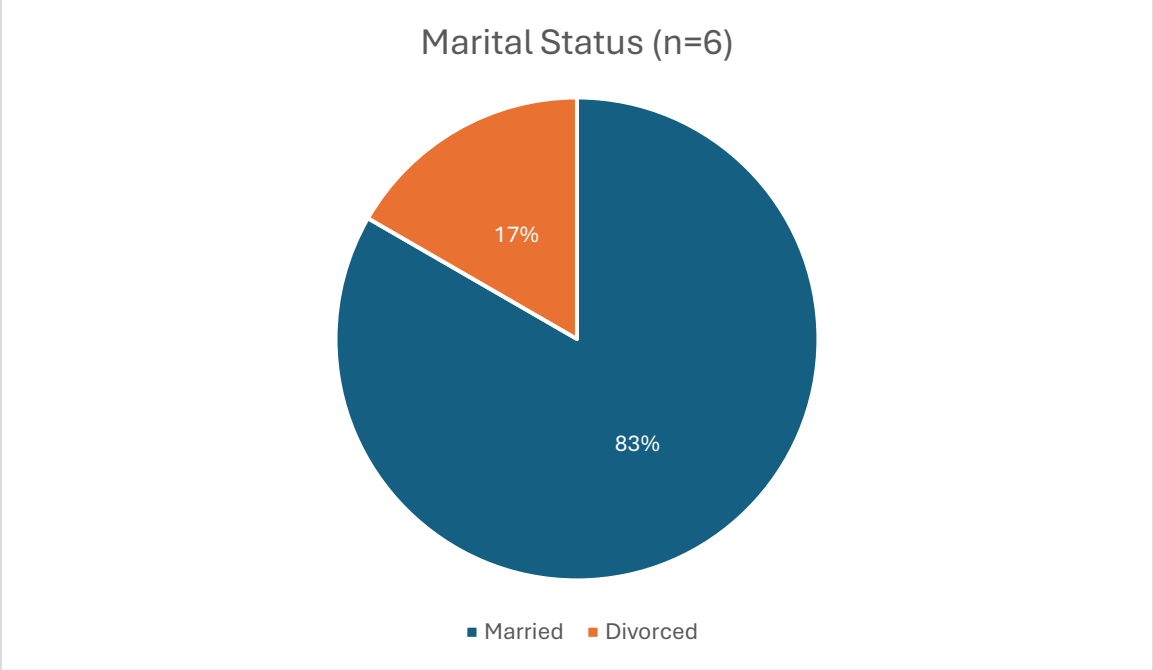

Figure 4.4 Marital status of participants

From this figure, it is clear that the majority of participants (83%) (5) are married and living with their spouses. Only one participant (mother) is divorced, and is the primary caregiver, while the father is still involved in the family.

4.2.1.3 Access to services

Figure 4.5 presents the services that participants have access to for their CWID.

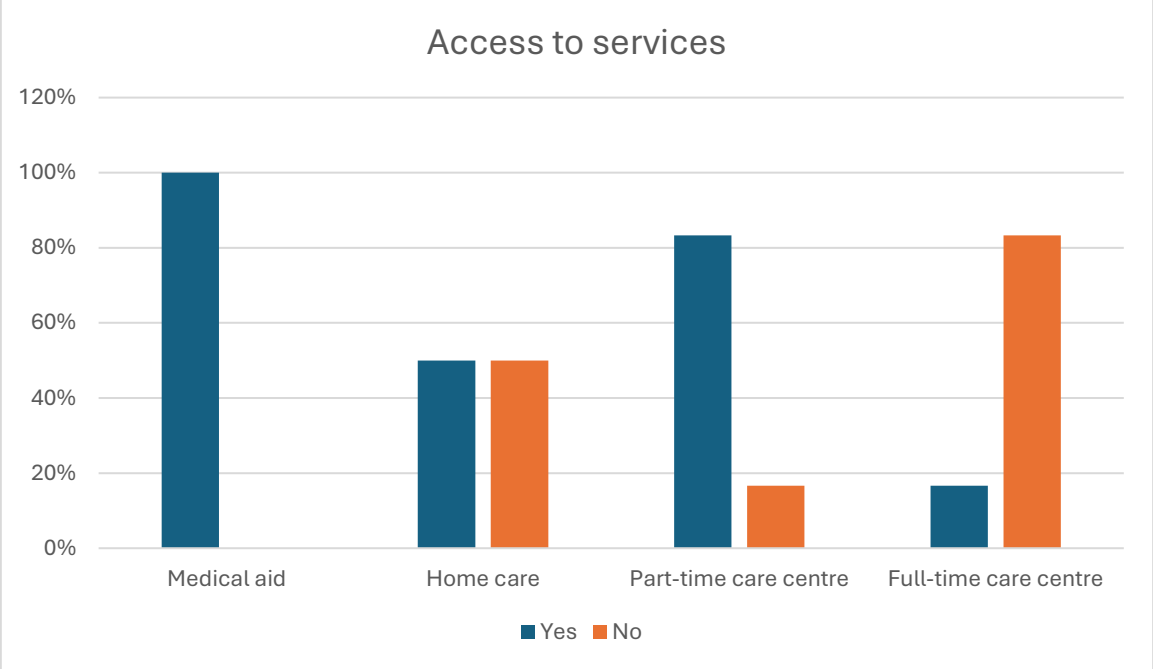

Figure 4.5 Participants' access to services

This figure shows how all participants have comprehensive medical aids contributing to the medical and therapeutic cost of caring for a CWID. All participants have access to a form of care facility, with the majority, 83% (5), having access to Apricot Tree Centre as a part-time facility. A minority (1), 17%, of participants have placed their child in a full-time care facility, as their care needs were beyond the scope of the family. Figure 4.5 shows that 50% (3) of participants have care workers or nannies who assist them at home with caring for the CWID. This data is contrary to other studies in South Africa (Mmangaliso & Lupuwana, 2021), that focused on poorer communities, emphasising the middle-income nature of this population sample.

4.2.1.4 Economic status

No in-depth income information was collected from the participants. Figure 4.6 indicates the employment status of the participants, while Figure 4.7 represents the housing situations of the participants.

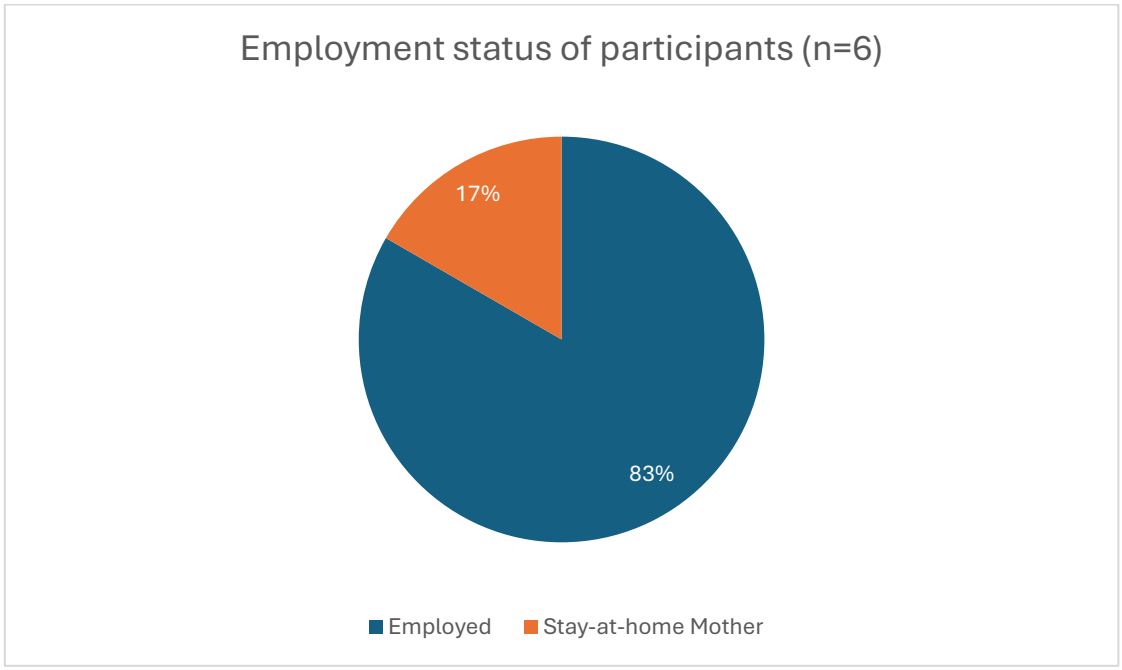

Figure 4.6 Employment status of participants

Figure 4.6 indicates that 83% (5) of participants are employed outside of the home. All participants work within a white-collar profession in finance, administration, human resources or health. One participant (17%) does not work outside of the home, not due to unemployment but rather lifestyle choices to be a stay-at-home mother. Furthermore, all participants have a spouse or ex-spouse who is employed and contributes to the caring of the CWID. Statistics South Africa (2022) estimate an unemployment rate of 35% in South Africa, highlighting the middle-income status of participants.

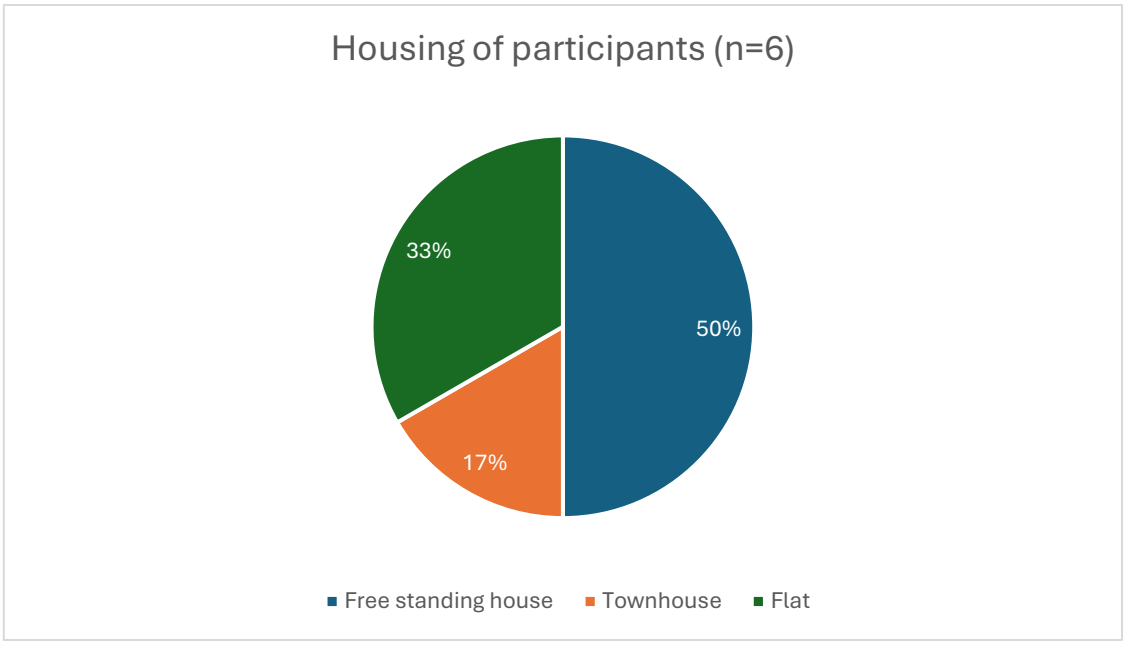

Figure 4.7 Housing of participants

From this figure, it is clear that 50% (3) of participants live in a free-standing house with their nuclear family, while 33% (2) of the participants stay in an apartment or flat. Furthermore, 17% (1) of participants stay in a townhouse. All participants live together as a nuclear family with no or limited extended family members.

4.2.1.5 Race

The race of participants is represented in Figure 4.8. Race refers to the grouping according to physical traits humans are divided accordingly (Merriam-Webster, 2023). Data on the race of participants are important in this study as it assists in understanding family, cultural and spiritual aspects of participants' experience.

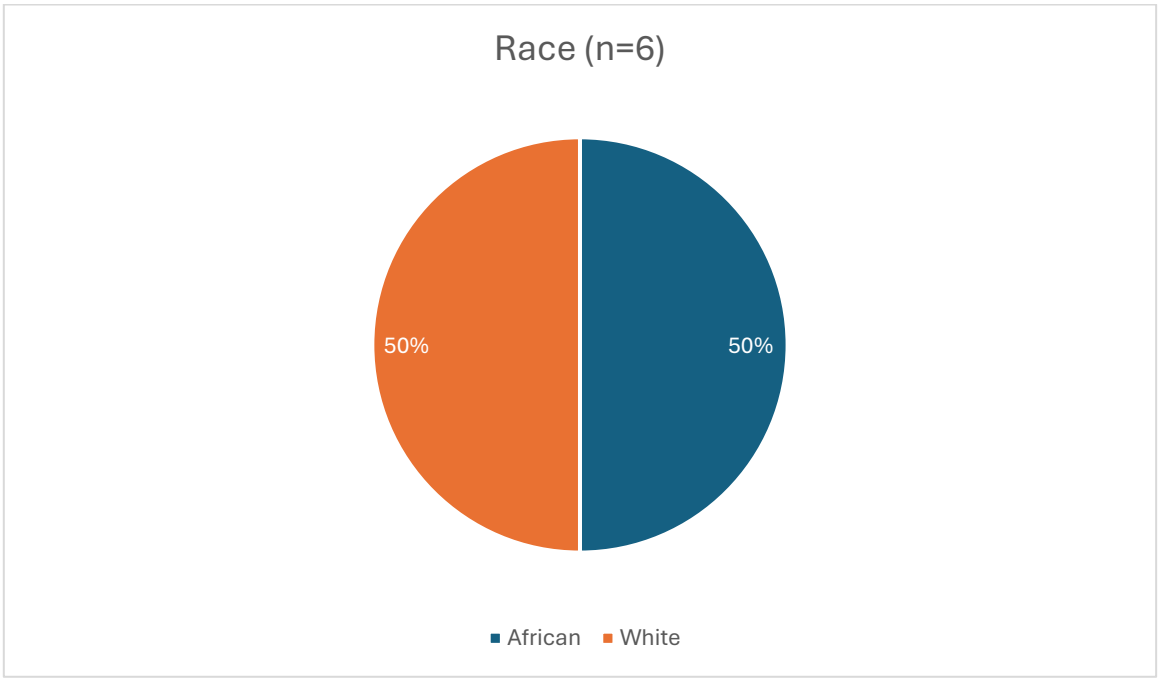

Figure 4.8 Race of participants

This figure reflects that 50% (3) of participants are African and 50% (3) are White. All participants are South African Citizens.

Subsequently, the thematic analysis is provided.

4.2.2 Thematic analysis

The findings of this study will be discussed according to the themes and sub-themes that emerged from the reflexive thematic analysis of the data. The interviews were recorded and then transcribed verbatim by the researcher. Transcriptions were used for code identification, and based on the codes identified in the data, themes and sub-

themes emerged from the data to answer the research question. Inductive coding was applied to discover codes, and literature was used to corroborate and provide insight into the findings. Verbatim interview quotes were used to substantiate the themes and sub-themes.

Table 4.2 shows the themes and sub-themes generated from the empirical data.

Table 4.2 Themes and Sub-themes from Data Analysis

Theme	Sub-theme
Phases of diagnosis and caring for a child with intellectual disability	Pre-diagnosis Process of diagnosis Emotional responses to diagnosis Emotional responses to living with the diagnosis
The implications of caring for a child with ID for the nuclear family	Impact of a child with intellectual disability on family function and dynamics Impact of caring for a child with intellectual disability on the marital relationship Limitations of the family experience Trade-offs families make to care for a child with intellectual disability
Caregiving experiences	Challenges caregivers face and the impact on their mental health Medical challenges caregivers face Caregiver burnout Behaviour and sleep challenges as a determinant for mental health of caregivers
Voices from the outside	Challenges and opinions from extended family Social and community views and response to intellectual disability Religion and spirituality
Identity, Self-worth, roles, expectations and dreams of parents	Identity and self-worth Roles and expectations Loss of dreams
Coping, resilience and support for parents	Finding ways to cope Support as a contributor to resilience Statements of resilience Acceptance, finding hope and meaning Positive aspects of caring for a child with intellectual disability
Services for parents caring for children with intellectual disability	Gaps in services identified Service recommendations

4.2.2.1 Theme 1: Phases of diagnosis and caring for a child with intellectual disability

A prominent theme that emerged from the data was the participants' journey, beginning with the child's birth and continuing through the stages of pre-diagnosis, the diagnostic process, adjusting to the diagnosis, and ultimately living with the ID diagnosis. Although

each participant's story differs, similar elements are featured across the data sets. This theme will look at the factors that impacted the mental health (MH) of the participants in the differing phases of diagnosis, as well as their emotional responses to each phase.

The sub-themes presented in this theme include pre-diagnosis, the diagnosis process, emotional responses to diagnosis, and emotional responses to living with the diagnosis.

Important biographical information for this theme is that one participant had a child that had features of a disorder at birth, one participant had birth complications, but no concerning features at discharge, and four participants had children that were discharged after birth as 'normal, healthy babies'.

4.2.2.1.1 Sub-theme 1.1: Pre-diagnosis

This sub-theme represents important factors prior to diagnosis of the child and the parent that impacted their process of diagnosis as described by the participants:

> ***P1**: "So, my daughter was born looking pretty normal. About 6 months, 8 months, between 6 and 8 months I started realising she's not doing what other kids her age are doing."*
>
> ***P2**: "But when she was born she was perfectly normal weight, meeting all the correct standards when they check…I noticed when she was about three months old. I have friends actually that we have kids around the same age. We share videos and pictures of what our kiddos are doing and around three months my friend's kids were pulling stuff and I was like, why is my kid not pulling stuff."*
>
> ***P3**: "Jane was then also born at 27 weeks of pregnancy. She weighed 985 g, stayed in NICU for four months. So, at that time when she was discharged, I didn't know that there was anything alarming."*
>
> ***P3**: "But at this point at home, I remember my dad would say that I didn't want to overthink it that much, where he would say, I did notice some signs that she's not meeting her milestones at the certain age that she's supposed to, but to me, it was because maybe she's a premmie."*
>
> ***P6**: "I had Sister first and then I had Jane, but we never knew there was anything wrong with her till the age of two and a half. Where the nursery school phoned me, said she had a seizure."*

Five out of the six participants indicated that at birth there was no indication that their child had an ID. Participants only realised that something was wrong when either their child did not meet developmental milestones or had their first seizures. Christianson, Zwane, Manga, Rosen, Venter, Downs and Kromberg (2002:93) confirm that comorbidities such as seizures and hearing loss are most often the facts that encourage parents to seek a diagnosis in South Africa, due to the lack of prenatal screening.

Several participants indicated that, once they realised their child was not meeting their developmental milestones, family, friends and even professionals discouraged them from investigating further. The following interview quotes describe the participants' experience:

> ***P2**: "And my daughter would just sit, and then I thought no there's something definitely wrong… My mom kept on saying yeah, but you didn't crawl so it could be fine. So yeah, I wouldn't sleep at night. That's how concerned I was. I would stay up at night, I would research exercises that I could do with her."*
>
> ***P1**: "My family constantly told me that I mustn't compare? And in my mommy heart I was like there is something wrong with my child."*

Participants described that they were convinced something was wrong, and it caused anxiety. No literature could be located to corroborate this finding. Still, it appears vital, as it represents the initial phase where participants did not receive the needed support from their support structures, whether formal or informal.

4.2.2.1.2 Sub-theme 1.2: Process of diagnosis

The following theme represents the process of diagnosis, the extensive medical tests and interactions with healthcare professionals. The following interview quotes confirm this sub-theme:

> ***P1**: Now in that time, the little movements in his eyes started getting worse, and I could see him having little contractions. So then we got him into the neurologist. He did an EEG, and it was found that he had epilepsy…"*
>
> ***P2**: "And then she says I mean, but we'd have to just run test. I can't really tell from face value. I'm gonna have to book you guys in we're gonna run a whole lot of tests and then we'll see what's wrong…She was diagnosed, and the doctor literally told me over the phone, and to say no this is what she has and it's uncurable and unfortunately and there's nothing that you can do about it, but continue with the therapies."*

> ***P3**: "And at 18 months, she had her first seizure, we rushed her to hospital. And when we got to hospital, they did an MRI. They did an overnight EEG. And the next day…the paediatrician then told us that no, her MRI, they did the test, and it came back that she's got brain damage."*
>
> ***P5**: "…but with the test that was done in Germany it came back normal…So she's really undiagnosed at this point."*

Participants indicate that emergency testing determined the diagnosis in some situations, while in other cases, it was scheduled testing due to parents seeking answers for developmental delays. Even after an ID diagnosis has been made, gene testing follows later. One participant's child is still undiagnosed after numerous tests. Another participant's first child remained undiagnosed until her second child was born with similar symptoms, which prompted genetic testing and a genetic diagnosis Spata-5 syndrome for both children. Patel et al. (2016:9) confirm that diagnoses of ID are highly individualised and require a multidisciplinary approach.

Participants had varying experiences with medical professionals, while some found them very supportive in the diagnosis process, and others felt traumatised by how the medical doctor delivered the diagnosis over the phone without offering support or information regarding the diagnosis. Isa et al. (2016:57) confirm this finding by emphasising the importance of education and professional support regarding the diagnosis and care of a CWID as a stress reduction agent.

4.2.2.1.3 Sub-theme 1.3: Emotional responses to diagnosis

The sub-theme of emotional responses to diagnosis focuses on the emotional responses upon and shortly after receiving the diagnosis. Participants describe their responses in the following interview quotes:

> ***P1**: And I remember that first initial time, just driving home crying, telling my husband I've done everything. I breastfed. I did this. You know, just that very angry feeling."*
>
> ***P2**: It did feel like going through grief and…Okay, why am I going through this and why is it only me? And why must we always go to therapies…"*
>
> ***P1**: "I cried because I was so grateful because that relief that it's not my fault. I never did anything wrong. I'm not a bad mother."*

> ***P1**: "I broke down crying because I was happy for my daughter to have an answer. But my little boy, he's got the exact same thing… I had so much hope for my son."*
>
> ***P4**: "The doctor said, no, this is, it looks like autism. Now, my nightmare started. So, that's one of the most terrible news I've ever heard in my life. It came as a shock."*
>
> ***P4**: "So I remember, I think, six or eight months into this diagnosis, I fell into depression."*
>
> ***P5**: "I think it started off with having some baby blues and then hearing all these negative things of what's wrong with her. That actually pushed me over the edge."*
>
> ***P5**: "…I never stopped. We spoke to people [overseas]. We tried to get her into a trial. We did a lot for her. See how we can help her and even almost make her normal…you wish for a long time that that's still going to be the case."*

A common response to the diagnosis was shock and grief. Participants also describe anger, guilt, self-pity, relief, loss of hope, denial and depression as part of their initial response to the diagnosis. Graf (2018:178) validates the participants' responses that initial reactions of shock, grief, denial, sadness and anger are critical emotional responses that allow participants time to find equilibrium later on.

4.2.2.1.4 Sub-theme 1.4: Emotional responses to living with a diagnosis

As significant adjustments have to be made in entering the role of a parent caring for a CWID, and participants move past the initial emotional responses to the diagnosis, different emotional responses surface. This sub-theme presents the emotional responses participants describe as they move towards living with a diagnosis. This sub-theme is at risk of overlapping with subsequent themes as many emotional responses are linked to various psychosocial factors participants encounter. The boundary of this theme will be the emotional response itself as an overarching theme in the participants' lives, rather than emotional responses to specific factors. This theme is confirmed in the following interview quotes:

> ***P2**: "Personally, I think yeah, it's just I always say I've literally been on survival mode ever since Jane was born. I don't think I've ever allowed... I can't relax.*

I can't and I can't get myself to just be Cujo and just be a person who's just relax."

***P1**: "I didn't know how to deal with any of my emotions, so used to just lash out and shout at her, and, you know, she would laugh."*

***P3**: "So it has affected me in the sense where you do go through a sense of depression, anxiety, a lot of worry."*

***P3**: "You still have moments where you still sometimes do think if you might have done something wrong."*

***P1**: "I did consider, like, maybe if I just take all these tablets, then everything will go away."*

***P3**: "And then it just became a lot. I just parked on the side and I literally started crying. I started crying because it was just a lot. It felt too much, and I know that prior to that period as well, I was having a lot of suicidal thoughts."*

***P6**: "And then we feel this heaviness and I know Jane's done this and she's done that."*

Participants experienced anger, blame, shame, excessive crying, depression, self-blame, anxiety, lack of emotional control, feelings of being overwhelmed or hopeless and ultimately, suicidal thoughts. Islam et al. (2022:216) and Graf (2018:178) similarly describe the emotional responses of parents caring for CWID. The overwhelming nature in which participants describe their emotional responses correlates with Staunton et al. (2020:5), finding that emotional responses directly impact the quality of life and MH of parents caring for CWID.

A clear distinction is visible in the various phases of caring for a CWID. Most of these emotional responses were universal to the sample group, and age and ethnicity did not significantly impact the participants' emotional responses. Experiences early in this journey impacted future responses to persons and events in some cases. In other instances, growth and the development of adaptation and resilience are visible throughout the participant experience.

With regards to the ESP underpinning this study, the researcher is of the opinion that although personal attributes and the micro-, meso-, and exosystemic factors in the participants' ecosystem impact the emotional responses, they do not safeguard the participant against emotional response. Graf (2018:178) highlights the importance of

such emotional responses as activators to positive adaptation to circumstances. These adaptations will be discussed in detail in Theme 6, under resilience and coping.

4.2.2.2 Theme 2: The implications of caring for a child with ID for the nuclear family

This theme arises from the participants' insights into how having a CWID impacts the entire family. This theme will focus on the nuclear family, which consists of parents and siblings of CWID. Sub-themes identified with regards to the nuclear family included the impact of a CWID on family function and dynamics; the positive and negative impact of caring for a CWID on the marital relationship; limitations the family experiences; and trade-offs the family make to care for a CWID.

4.2.2.2.1 Sub-theme 2.1: Impact of a child with intellectual disability on family function and dynamics

This theme focuses on the impact a CWID has on the family dynamics, functioning and roles in the family, as a child with an ID has a rippling effect throughout the family. (Hanson, 2013:101). The following interview quotes indicate the areas where ID impact the family:

> ***P3**: "And at the same time, while you're focusing on Jane, you've got another child that you need to balance out, you know."*
>
> ***P3**: ". And at the same time, then it became, okay, now we need to try and find a school for him, which will be also a good school for him so that as much as our finances are already tight, it's fine, but we just need to ensure that he doesn't feel the gap."*
>
> ***P4**: " So you can imagine how my life turned around because I started now not to give my other child, who was seven years old by then, I couldn't give him the attention that I used to. He was very happy with the child, but now suddenly things have changed."*
>
> ***P6**: "It's always been about Jane and Sister was sort of shoved aside because you find you (sister) can cope, you can deal with everything."*

Participants experience that the needs of the ID child in the family are prioritised, and other children are neglected in terms of finances, support and time spent with parents. Each parent with other children expressed the desire to prioritise the needs of their other

children better, but found it hard to do so. Parents express guilt over the challenges of their other children. Griffith and Hastings (2014:419) report on parents experiencing a lack of time and resources for their other children confirms this finding.

Parents describe their realisation that the care demands of a CWID impact their relationship with their other children below:

> ***P4**: "I don't have time where I go out with them alone. I want to do that, but I think they have already given up on that because every time I suggest that to his brother and say, let's go after school, let's go and have coffee. He says, no, don't worry about it."*

Parents find caring for a CWID so all-consuming that they have difficulty relating to their other children, parenting them, and establishing close relationships with them. Most studies (Hanson, 2013:101; Hastings, 2016:188) indicate that families with CWID experience more significant stressors regarding roles and relationships, but siblings are not negatively affected in the long term. However, the participants' perceptions regarding this are still important to note as it has an impact on their MH.

In the following interview quotes, participants express how caring for a CWID causes disruptions to normal family function:

> ***P4**: "So, already there was some sort of disturbance in how we were living. We had to go all out to accommodate him."*
>
> ***P4**: "There are good. However, I still want to say, I expect good things to come, but the damage that comes with the diagnosis, it's extensive."*
>
> ***P6**: "And it's also been hard for Sister because when she would come visit, she would stay at the boyfriend's house because then (when she stay at the house) her sister would want to hit her."*
>
> ***P6**: "Because then my husband would scream. He doesn't have also a lot of patience. And he would also say, just give her whatever she wants, just keep the peace."*

Participants indicate that caring for a CWID is destructive and disruptive to normal family patterns. Family members form maladaptive coping mechanisms such as aggression, overcompensation and isolation of family members. Graf (2018:177) argue that all families undergo periods of dysfunction to gain equilibrium, ultimately explains the universality of this theme. However, failure to establish equilibrium will have long-term detrimental effects on all family members.

Having a CWID can also positively influence family dynamics, as reflected in the interview quotes below:

> ***P3**: "He has not been exposed to those narratives that I was exposed to. Because he's growing up with Jane, he's not seeing that she's different. He's seeing that this is my sister…"*
>
> ***P6**: My daughter's got compassion for people. She'll help anyone. She just loves people. She will put people before her. She's got such a good heart."*

Participants can see how being a sibling of a CWID also positively influences their other children. Participants mentioned that children grow up without prejudice or stigmatised views of persons who are different. One participant noted that her other child became a compassionate and selfless person as a result of growing up with a sibling with ID. This view is supported by (Marini:183), who found that siblings of CWID are more responsible and compassionate than their peers. Irrespective of the positive aspects identified by participants the biographical data indicate that most participants still opted to not have additional children after the birth of their CWID

4.2.2.2.2 Sub-theme 2.2: Impact of caring for a child with intellectual disability on the marital relationship

Marital relationships come with their own set of challenges that must be navigated to build a strong and cohesive relationship. This sub-theme explores the impact of caring for a CWID on the marital relationship. One participant is recently divorced, and the participants' views on how their CWID contributed to dissolving the marriage are also considered. The following interview quotes reflect the positive aspects of the participants' marital relationship:

> ***P4**: "And one of the things was my husband was very supportive. We were in this together. But I think he slowly learnt about the condition."*
>
> ***P1**: "And like my husband said, for now, 'let's just get you better because if your mental health is not good, you're physically not better, none of this can work."*
>
> ***P5**: "My husband's very supportive."*
>
> ***P1**: "But I think the biggest thing is that the fact that we do have that long love, that big connection in the middle where both of us know what's important."*

> ***P3**: "I just withdraw and I say, hubby, just like take care of that. I'll do the bare minimum and you just have to do everything else."*

Most participants experience their spouses as being supportive and 'there for them'. Participants mainly express the awareness of their support when they are emotionally and physically exhausted. Beighton and Wills (2019:1271) confirm this finding that spousal support mitigates parental distress in caring for CWID. One participant expressed the role of commitment and love in the relationship, which bonds them to face the challenges head-on. The fact that 83% of participants are married, may slant this positive finding. However, the value of spousal support is still worth noting.

Participants reflected in the following interview quotes about the challenges in their marital relationship:

> ***P1**: We have to remember that we are a couple. And we start forgetting that because our focus is so on our children."*
>
> ***P2**: And so definitely caring for her also caused a huge rift when it comes to we would want to do things differently and finances were also a huge issue.*
>
> ***P2**: "And I think Jane's dad and I we were never aligned when it comes to what's could be best for her. We would care for her differently. I would push the therapies and he would say let's just pray about it. I would push her going to school and it would be why don't she just stay at home."*
>
> ***P6**: "And it put a lot of strain on our marriage, a lot of fighting."*
>
> ***P6**: "I think because of her behaviour since a baby, I was the one that always had to look after her. My husband was out with his friends drinking, so it was very hard."*

The above interview quotes indicate challenges to the marital relationship, such as prioritising a child's needs above marital relationships, opposing views on how to care for CWID, conflict due to problem behaviour of the CWID, substance abuse, marital tension, and disagreements on finances. These findings are confirmed by Hanson (2013:101) findings that chronic stress and behavioural problems play a role in marital discord.

Although participants view themselves as the primary caregivers and allude to an unequal division of caregiving tasks, they measure support from spouses in terms of emotional support and do not share the caregiving burden. These findings should be viewed with the understanding that four out of six participants portrayed their marital

relationship as positive and satisfactory in respect of five of the six participants being married as indicated in the biographical data.

4.2.2.2.3 Sub-theme 2.3: Limitations the family experience

Across data sets, participants reported limitations their families experienced while caring for a CWID. This sub-theme will explore the type of limitations experienced and the impact thereof on the families. The following interview quotes confirm this sub-theme:

> ***P6**: "Because you can't have people over and you can't go away, you know, things like that. Can't go meet a friend in the week for dinner because Jane's home."*
>
> ***P5**: ". But I think it's the fact that they want to do certain things, which we cannot do. They want to have a quick braai, at a certain time that's not maybe for us to do because that's her nap time. Or if the place where they want to go like a noisy restaurant for a family gathering we have to sit out."*
>
> ***P1**: "It's very hard to realise you can't go on holidays with your family."*
>
> ***P4**: "We have stopped going to our regular destinations before Johnny was there. We have stopped because those destinations do not work out for Johnny."*
>
> ***P5**: "Like my nephew he was with the other nephew in [international destination] now recently, and they said let's do a Christmas in [international destination] next year. I said to him in what world do you live? If Elon Musk can't get me there within an hour, I cannot be there. You know those are the kind of things we have to sit out on. it's just not… You can't just pack up and go and do something everything must always be is, there a microwave, is there no stairs but a lift?"*
>
> ***P6**: "Um, we couldn't really take her out. She… we used to, when she was smaller, we would go to Spur, but it's just got hard."*

Participants report that the practical needs and behavioural challenges of their CWID cause them to experience limitations. These limitations include places where they can go, visiting friends, having friends over, travelling, attending family gatherings and other social settings. Limitations on movement and ability to attend social events were communicated as disappointments, unmet expectations, and desires. The biographical data indicate that these limitations are not due to financial constraints, emphasising the

force of societal constraints. No literature was found that directly reports the limitations families experience. Still, the impact of limitations alludes to the findings of Hanson (2013:101), who found that families are more likely to experience isolation and have to adjust expectations of family life.

4.2.2.2.4 Sub-theme 2.4: Trade-offs families make to care for a child with intellectual disability

This sub-theme reports the sacrifices families make to care for their CWID sufficiently. Merriam-Webster (2023) defines trade-offs as "a balancing of factors, all of which are not attainable at the same time." The following interview quotes reflect the trade-offs families make:

> ***P1**: "I actually cried and said to him, 'I don't want you to go' [work overseas]. And then you have to look at one another and go like, 'I can stay here but, I mean, we move to a shack. You know, there's things we have to work on. And my kids' health or my kids' medication is important, so we have to give up."*
>
> ***P3**: "I'm going above and beyond, if it means that I had to move all the way to another suburb so that I can be closer to Jane's school, I'm not looking at the, like for example, the expenses. I'm just looking at what my child needs in terms of therapy."*
>
> ***P3**: "hubby has to work a lot of overtime hours over the weekend to cover for costs. Then it leads me to having to take care of the kids."*
>
> ***P1**: "he was breastfed for 4 weeks, because when I started introducing him to his sister, Jane thought he's like eating me, so she kept on pulling her brother off. So I had to put him onto bottles. So you know it's those little things …"*

Most trade-offs reported by participants were regarding access to services and meeting their financial needs to care for CWID. Participants reported that they or their spouses made career choices prioritising financial stability, at the expense of family time and support or abandoned parental ideals, such as breastfeeding, to meet their children's needs better. Three participants indicated they relocated and moved further away from their support system to be closer to a good care centre. Most trade-offs come at the expense of the parents' well-being in order to meet the needs of their CWID.

Participants experienced that caring for a CWID has significant implications for their whole family. Although literature (Graf, 2018:177; Hanson, 2013:101; Hastings,

2016:188) confirms that caring for a CWID has positive and negative aspects, participants focused significantly more on the negative aspects, while positive aspects within the family context were glanced over. McConnell et al. (2014:11) argue that poverty and financial distress are a predictor of poor outcomes for families and are difficult to assess in this study, as all participants are middle-class and, according to South African standards, have sufficient access to resources and support.

The ESP highlights that the interactions between family members, and how their behaviours and well-being influence one another, are fundamental to the abovementioned findings (Hastings, 2016:178). The findings accentuate that no individual can be viewed in isolation (Teater, 2021:48). Family dynamics are concentrated in the micro and meso systems of immediate contacts and the relationships, though it does not exclude other systems' impact on the parent.

4.2.2.3 Theme 3: Caregiving experiences

This theme was generated from the participants' experiences of caring for their children, the demands on them as caregivers, the challenges they experience, their experience of precipitating factors leading to caregiver burnout, challenges related to medical needs, and behavioural and sleep problems. A caregiver is a person who attends to the needs and daily care requirements of a person who is not able to care for themselves independently (APA, 2024a). The person who shoulders most of the responsibility is called a primary caregiver (APA, 2024a). All participants play the role of primary caregiver for their children, offering an in-depth understanding of the roles and responsibilities of caregivers of CWID. One participant placed her child in a full-time care facility approximately a month prior to the interview.

Data analysis revealed that the parents' role as caregivers is often all-consuming. Sub-themes identified included caregiving experiences and challenges, the never-ending burden of caregiving and burnout, the challenges of dealing with the medical needs of CWID, and behaviour and sleep disturbances as determinants of poor MH outcomes for caregivers.

4.2.2.3.1 Sub-theme 3.1: Challenges caregivers face and the impact on their mental health

This sub-theme explores the challenges that participants identify in caregiving and how they experience the impact of these challenges on their MH. The following interview quotes confirm this theme:

> ***P2**: "…one thing that I would think about is what happens when I'm gone because I'm obviously her primary care giver. I mean dad is here. But what happens when I'm gone and I start thinking about do I want to put her into the care facility that I trust or family member and…I realise that she gets older it's a huge burden to put another family member to say could you please be my daughter's guardian?"*
>
> ***P3**: "So, will my mom actually do the right thing, you know? And it's not that you're thinking that people are incompetent, it's not that, it's just that you… it's just that I think that worry to say, is she safe? Is she okay? If she does have a seizure and I'm not there, will they be able to actually remember what they need to do?"*
>
> ***P4**: "…because I was alone. Alone in that having to care for him."*
>
> ***P5**: "I do feel a little bit anxious when I know like the weekend, for instance. My husband, they went to xxx for the weekend. So he then leaves me all alone. And I feel I do feel anxious before the week before then."*

The participants expressed anxiety as an underlying factor in various aspects. Anxiety ranges from concerns regarding the future care of the child, anxiety and fear of being alone with the child, and underlying anxiety in the absence of the child. Participants express the difficulty in trusting others with the care of their child while acknowledging the continuous and never-ending burden of care. This correlates with the findings of Griffith and Hastings (2014:416) and Masulani-Mwale et al. (2016:5) where a caregiver often functions in a continuous state of hypervigilance and a never-ending care burden. Isa et al. (2016:73) emphasise parents' anxiety regarding their child's future care. Whether a caregiver is married or single, they experience that they are rather alone in the caregiving responsibility, though they do not feel resentment towards their spouse for this.

The following interview quotes present the all-consuming nature of caregiving:

> ***P3**: "I think as caregivers we go through, we go through that mode of being a caregiver, and we move away from being like a mother. We always functioning on being a caregiver, which requires us to be active 24/7, and we haven't identify or found ways to sometimes pull ourselves from caregiving and just being a mom. You are always a caregiver. You don't view yourself as a mother but you view yourself as someone who has to care for someone else, and because of that, it leaves you in a bad situation because you can't even withdraw from that you are always in that mode."*

Participants expressed the consuming nature of caregiving, while one participant expressed this as a loss of their identity as a mother. Peer and Hillman (2014:92) articulate this phenomenon as the caregiver burden overwhelming the parents' ability to effectively parent their child, leading to long-term relationship challenges in the family.

Participants seem to be aware of the fact that their well-being and the child's well-being are interrelated (Hatton & Emerson, 2015:27). Participants reflect on this interrelatedness as follows:

> ***P1**: "Because I had to realise that every time Jonny goes through a dip, I go through a dip. And he is really struggling."*

> ***P3**: "Like I can't be burned out because my child requires me to be there, you know. And not knowing that you are actually running on low."*

Participants express awareness that their MH well-being impacts the well-being of their child. However, in the light of the cost of MH counselling, and already existing strain on their resources and time, participants experience this interrelatedness as a burden. Biographical data indicate that all participants have medical aid, but this does not assist in access to MH services.

4.2.2.3.2 Sub-theme 3.2: Medical challenges caregivers face

This sub-theme represents the challenges parents face in their role as caregivers in meeting their children's medical needs and coping with the demands of the children's ID and comorbidities. All participants' children have had significant medical needs at some stage of life; while some have outgrown it, others' medical conditions have worsened as they got older. Staunton et al. (2020:5) emphasise that many of the medical needs and challenges are related to comorbid conditions rather than the ID

condition itself. As caregivers, the parents have the responsibility to manage medical conditions daily, navigate the medical system and make medical care decisions for their children. The following interview quotes confirms this sub-theme:

> ***P1:*** *"You know. And then it was just how to start juggling the thing. Now the problem is, and this is where us totally fell apart because now you've been doing this with Jane for 11 years. You just found out your little boy has got issues. Now you're trying to get everything to stabilise, and instead of Johnny getting to his medication and be like his sister on the same like calm and everything is okay… The same applies to Johnny but he started getting worse and worse and worse."*
>
> ***P2****: "I mean it's strenuous for me, when I'm sitting on that chair day and night and I see I can't imagine what her little body is going through. So I think seeing her going through the Pricks getting all those pipes in and out, the feeding tubes, I think it has been a very traumatic experience for me, just seeing her in that state, especially because I know that she's a child that's full of life. Every single time when we do get admitted for that long she comes back… obviously, she would have regressed. Yeah, it's definitely you going through that: up and down; back and forth. Death to life has definitely been the worst experience, to be honest."*
>
> ***P5****: "Anxiety for me is more in fact of if her face doesn't look nice for me and I think she's going to have a fit. So, I'm very anxious and most of the time nothing happens."*

Participants indicated that they found it particularly difficult and stressful to manage seizures, the medical needs of multiple CWID, and serious illnesses and hospitalisations. A study by Mori et al. (2018:1662) confirms that complex comorbidities and severe ID diagnosis increase medical, physical and day-to-day care responsibilities for caregivers, resulting in a lower quality of life for these caregivers.

Several participant's children are non-verbal, meaning they are not able to communicate with clarity. Participants with non-verbal children find medical care challenging, as illustrated in the following interview quotes:

> ***P5****: "I think the only thing I want to get to is that when she's in pain and she doesn't just show me something hurts, she must show me where it is. I want to get to that point still."*

> ***P6**: "So I've had to rush her to hospital not knowing what's going on. So we have still taken her to hospital a lot and then crying and showing us her tummy and she can't tell us. Then we've got to do x-rays and blood tests."*

Participants experience it as stressful that their non-verbal children are not able to communicate with them regarding ailments and pain, leaving it up to them to determine factors that may ail the child or require costly medical tests to determine what is wrong. Staunton et al. (2020:1) find that non-verbal behaviour increases the stress and anxiety experienced by the caregiver, confirming this finding.

4.2.2.3.3 Sub-theme 3.3: Caregiver burnout

As mentioned, caring for a child with severe to profound ID can be an extremely demanding task. The sub-theme represents the participants' experience of factors that contribute to burnout. When participants talk about burnout, it is mostly in the context of the never-ending demands of caregiving and emotional exhaustion, as seen below:

> ***P1**: "When I couldn't be like…You know when you stop feeling, that's when you realise there's something wrong."*
>
> ***P4**: Even when I'm at work, I would get calls that he's doing 1–2-3. What do we need to do? He's not eating. He's not doing that. He's not, um, I couldn't even, when I go to the shops, I need to time myself that I need to be quick. Like, there was no time to relax. Even at work, concentrating, like, for me to be there the whole eight hours. At the back of my mind, I couldn't even relax… What did he do this time? What did he break?"*
>
> ***P3**: "And I feel that often we have to pour out and no one is pouring in."*
>
> ***P6**: "I think when you emotionally just are finished, you cry all the time. You just can't cope anymore."*

Participants describe the burden of caregiving as being never-ending, continually requiring them to give more than they receive, never having a moment's rest, and feeling like they become emotionally undone. These findings are congruent with Lima-Rodríguez (2018:94); Mmangaliso and Lupuwana (2021:15) findings that continued care burden and never-ending responsibility are likely to lead to emotional exhaustion and caregiver burnout. This translates to an ever-present anxiousness in parents caring for a CWID. Participants' descriptions of 'stop feeling' and 'emotionally finished' correlate with the assessment of (Perkins & Hewitt, 2016:2177) of burnout as feelings

of apathy and emotional exhaustion. Burnout in the parent can impact the interaction of parents with their microsystem, known as the mesosystem (Teater, 2021:50), directly impacting the ecosystem of the CWID and other family members, highlighting the importance of understanding factors leading to caregiver burnout.

4.2.2.3.4 Sub-Theme 3.4: Behaviour and sleep challenges as a determinant for mental health of caregivers

This theme explores participants' experiences of behavioural and sleep challenges and how it affected their MH. The following interview quotes represent participants' challenges sleep disturbances:

> ***P4**: "But then he started not to sleep. He wanted something to comfort him, but I would go until one o'clock without him sleeping. So, I struggled for a long time. I was slowly, gradually falling into a pit of depression, dealing with this new diagnosis and not necessarily knowing how to deal with him, care for him."*
>
> ***P4**: "One of the terrible things that threw me to the lowest point in my life is not sleeping. He couldn't sleep."*
>
> ***P5**: "I mean they don't sleep. She slept an hour in the day and an hour in the night. I wanted to slash my wrist at that point."*
>
> ***P5**: "Those were tough times. It was a very, very tough times. I really, really just wanted to run away. I wanted her always to become non-existent at that point in time."*

Participants indicated that lack of sleep, especially when the children were younger and often still undiagnosed, was the precipitating factor to their lowest point, thoughts of suicide or MH crisis. Sleep challenges are well documented as risk factors in poor quality of life and MH outcomes for caregivers of CWID (Mori et al., 2018).

The following interview quotes illustrate the behavioural challenges and the impact of those challenges on the MH of the participants:

> ***P6**: "So with her behaviour, I think I just gave her away her way with everything. Gave in and she knows I'm soft. So I think she took total advantage. She used to bite me, hit me, throw food."*

***P6**: "We could also, if the behaviour was fine, we could have a visitor here or have people for dinner, but we just couldn't because of her behaviour. Grabbing people's food. Seeking negative attention."*

***P6**: "Where you just can't control this child. Yes. And then I feel that I have failed and I have given, I blame myself for her behaviour because I've given into her when she was small."*

***P6**: Because someone was seriously going to get hurt. Either she was going to seriously hurt herself or we were going to get hurt."*

***P4**: "Because now, like I'm saying, the impact of me giving in in every situation where when he wants this, I just give because I don't want drama. I'm too stressed to deal with drama. Now I'm reaping what I sowed at that time."*

The interviews revealed that participants' MH is significantly affected by the behavioural challenges of their CWID. Participants indicate the experience of self-blame, social isolation, emotional distress, lack of control and fear of safety for self and others due to behavioural challenges. Literature supports the participants' experience that behavioural problems offer significant challenges for families in keeping family members safe, restricting the family's ability to engage in social settings and in finding care support (Mazzucchelli et al., 2019:755). Griffith and Hastings (2014:416) description of physical harm and injury to caregivers and family confirms the participants' experience of behavioural challenges. Participants indicate that they feel their parenting skills are to blame for the behavioural problems, which can relate to the understanding that parental distress and child behavioural challenges are strongly related. However, the literature instead supports that ID often presents with significant behavioural problems and that the relationship between parenting skills and behavioural challenges is much more complex than poor parenting (McConnell et al., 2014:11). Peer and Hillman (2014:92) concur that juggling emotional exhaustion and stress from caregiving can affect parents' parenting capacity, but does not connect it to behavioural problems. These perceptions of participants may be more linked to identity, role, and expectations, which will be discussed in the next theme. In light of the biographical data, no similarities can be found between type of diagnosis and behavioural problems.

This theme highlights the multifaceted challenges faced by primary caregivers of CWID. The participants' experiences emphasise the immense responsibility and personal sacrifices inherent in caregiving roles, particularly related to medical complexities, behavioural issues, and the relentless demands of daily care. This theme highlights the

significant impact caregiving challenges have on caregivers' MH, illustrating how anxiety, burnout, and a loss of personal identity are pervasive factors impacting their MH. This theme underscores the interaction (mesosystem) between the individual and microsystem and its impact in the individual (Teater, 2021:50).

4.2.2.4 Theme 4: Voices from the outside

This theme represents the beliefs, perceptions and behaviour of various systems outside the participants' nuclear family in response to CWID. This theme describes the participants' experience and response to such behaviour and how it impacts the MH of the parents caring for CWID. The theme name is derived from a comment made by a participant, appropriately summarising the experience of participants:

> ***P3**: "So it is difficult because while you're trying to walk this journey, you're getting a lot of noise from people from the outside."*

The sub-themes will explore various systems, including the extended family, participants' social settings and communities, cultural settings and religious institutions. Participants described religion and extended family as both sources of challenges and as supportive structures, depending on their experiences. For clarity, the positive aspects of support from family, communities, and religion are discussed under coping and resilience in Theme 6.

4.2.2.4.1 Sub-theme 4.1: Challenges and opinions from extended family

This sub-theme presents the challenges and opinions participants experience from extended family. All participants identified their primary support person as someone within their extended family, but five out of the six participants indicated that the opinions and behaviour of extended family members were a major source of distress for them. The following interview quotes confirm this sub-theme:

> ***P2**: "And then there's obviously extended family that comes through and says no guys don't spend so much money, lets just pray and trust God for it."*

> ***P3**: "But when we go to your family, the only thing that they complain about is money. The only thing that they complain about is expenses, you know? So there was a level of tension between us where I would fight verbally for Jane and he would want to fight, but at the same time, it's his family, you know?"*

> ***P3**: "I've experienced that a lot in a sense, even family members will be like, no, let's take Jane to a traditional healer, you know. They will try to sort out things like epilepsy and things like that, you know. I even had my parents as well, who I think at first, when they were still getting to understand Jane's diagnosis, they were also quick to go to that point."*

Participants indicated that extended family has definite opinions of how a child's diagnosis should be approached, how money should be spent on the CWID, and what treatments should be pursued. The opinions of the extended family were often at odds with medical and therapeutic advice and with the parents' own goals for caring for their CWID. Some participants indicated that the opinions of the extended family cause tension in their marital relationship and family relationships. For African participants, the views of the extended family were intertwined with cultural and religious beliefs. This interconnectedness is supported by the description of Kpanake (2018:198) of African personhood consisting of spirituality, family, clan, community, culture and self.

Participants indicated difficulty in fitting their child's special needs into the functioning of the extended family. The interview quotes below confirm this:

> ***P2**: "I would find myself saying I need to just lock her in this room with her nanny and I'll tell her nanny don't let her out of this room because firstly people would be like, why are you not walking? You're such a big girl. And in essence when people obviously had left and it was just somewhat immediate family she would come out and the old grannies would be like, why is this child not walking? And they would shouted at her: Stand up and walk! Jane, Stand up and walk."*

> ***P6**: "Terrible that they cannot accept my child and they don't accept her as being different because of her behaviour. And that she can't speak."*

> ***P2**: "So when I eventually told my grand about my daughter's diagnosis my gran was like: "Don't tell people that! What is that? Keep quiet! The doctors are talking rubbish and she refused to accept it, point blank. Because in her days disability is taboo."*

The data suggest that participants struggle to integrate into their extended families. They report feeling that their families do not accept their child with an ID and often feel ignored or rejected. Participants experience that the diagnosis is not acknowledged, leading family members to expect "normal" behaviour from a CWID. Similar to findings in the study of Mmangaliso and Lupuwana (2021:9), participants indicated a similar lack

of support and understanding within their extended family and their social and community environments. These findings are consistent with Mkabile and Swartz (2020:6) and Chauke et al. (2021:5) findings that the extended family was sought out for support, but the extended family had difficulty coming to terms with the diagnosis, accepting the CWID, and providing the support the parents require. These findings are supported by the biographical details that indicated that no participants live with extended family, but rather as a nuclear family, even in cases where it is contrary to cultural norms. It can be hypothesised that participants minimise their micro system, as a protective measure to minimise interactional burden and conflict within relationships.

4.2.2.4.2 Sub-theme 4.2: Social and community views and response to intellectual disability

This sub-theme reflects participants' experiences within their community and social contexts, focusing on how people respond to ID, the remarks made about their children's behaviour and needs, and the effect parenting a CWID has on their social interactions and friendships. The following interview quotes capture this sub-theme:

> ***P1**: "When people start staring, I will just go like, you know what, you stare. And if someone asks me something, I will answer politely."*
>
> ***P5**: "You know the funny fact is it's older people that's staring, not kids…"*
>
> ***P6**: "And here, people hide their kids away in this country…You don't see special needs because we judge people. Look at us. I have taken her to the bird and monkey park before. People just stare. And it's so uncomfortable."*
>
> ***P1**: "A lot of people will either feel very sorry, Other people will go like, just don't bring this close to me, I might get a disease. And there's a lot of people that go like, that's a punishment."*
>
> ***P5**: "People should not be feeling sorry for me….I don't want to be the person that they feel sorry for."*
>
> ***P1**: "These two kids, they don't feel sorry. They don't even know what the word sorry means. Because they just want to be happy, loved. Just give them a hug."*

Participants experience that within South Africa, differently abled people are rare in public and cause people to stare, making parents uncomfortable. One participant indicated that South African communities are so unwelcoming to special needs, that

parents hide their children away. All participants indicated that they shy away from taking their children into public to avoid the stares and comments made by people. Most participants indicated that they have familiar places where they would shop and eat and where their children are known, and they find it stressful to venture to other unfamiliar places. Many participants indicated that they often receive pity in public for having a CWID. All participants indicated this was a negative experience and did not want pity. Merriam-Webster (2023) defines pity as "sympathetic sorrow for one suffering, distressed, or unhappy", although it is generally viewed as being absent of compassion, making it aloof and contentious. Participants' negative experiences are confirmed by the classification of pity by Scior (2016:5) as a form of stigmatisation. Participants generally experience pity to be distant and imply that their CWID is a sorrow or a hardship. The following interview quote summarises the participant's experience of pity:

> ***P5**: "And I don't want you to feel sorry for my life. I'm coping. And we cope as a family and we've actually very happy."*

This quote indicates that participants experience pity as an assumption that having a CWID is tragic and a hardship, confirming the assertion of Minnes et al. (2015:557) that the "tragic" view of disability is a form of stigmatisation in itself.

The following interview quotes present the judgement experience of participants:

> ***P6**: "There have been people that have judged me and said, I have thrown my child away. …And they've said, how could they put her in a home? You know, things like that."*
>
> ***P1**: "… your supporting people will tell you, your daughter is naughty. You need to be a more strict mother, because we don't have any proof that there's physically a reason. That she's like that. So people will call, will tell me I must not baby her. I must not, you know, I need to be more firm."*
>
> ***P6**: "People would judge and just say, control your child. She's naughty. Very easy to talk, but not in our situation."*

During the interview, it emerged that participants often feel judged and misunderstood by outside voices. Participants felt judged for how they parent their children, their children's behaviour, and their choices regarding the care of their CWID. All participants indicated they realised they should not listen to those 'voices', but still felt judged.

Participants found that caring for a CWID impacts their ability to attend social events and nurture friendships, as presented in the following interview quotes:

***P2**: "I always tell my friends that I'm on survival mode and they always like but you're doing such a great job. I'm like, but I'm on survival mode."*

***P3**: "It's so isolating in a sense that even amongst my friends, I wouldn't have people who would understand the journey that I'm going through."*

***P5**: Your friends will understand but they will stop inviting you because you always say no.*

Participants indicated that they could not attend social events with friends and invest in friendships. Furthermore, they feel poorly understood by their friends as they view them as strong and capable and not 'seeing' the strain they are under. Being misunderstood by friends, combined with the challenges of social interaction, causes participants to feel isolated and alone in their friendships. (Masulani-Mwale et al., 2016:872; Shahali et al., 2024:9) study similarly found that the social interactions of parents caring for CWID, are disrupted by caregiving responsibilities, leading to isolation and poor MH outcomes.

4.2.2.4.3 Sub-Theme 4.3: Religion and spirituality

This sub-theme explores the experience of participants regarding religion and how it impacts them as parents caring for CWID. This sub-theme will focus on parents' negative experiences with religion as an outside voice in their experience. Positive aspects and personal spiritual beliefs and views are discussed in Theme 6. The following interview quotes confirm the negative religious experiences of the participants:

***P5**: "And she wants to come and pray for us… And then she started to pray, but, you know, started very normal in prayer. And then all of a sudden shout and say: let this demon go out of this child… I was shocked. I was absolutely shocked."*

***P2**: "And then there's obviously extended family that comes through and says no guys don't spend so much money, lets just pray and trust God for it. And I don't take away from that. But for me, it's like but we need to do something too."*

***P3**: "Even that was a topic to say, 'oh, probably now, because the husband is not using their dad's surname, there now needs to be a thing where we need to go to the father, and they have to appeal to the ancestors in terms of Jane. If maybe this is a sign from the ancestors that because my husband and his*

parents didn't do things correctly according to our culture, now it's like Jane is the result of that."

***P3**: "But I remember the pastor was like, no, we need to pray for the child so that these demons can come out. And I'm like, but what do you mean, these demons? My child doesn't have any demons. She's got epilepsy…"*

***P3**: "So I think for me, with churches, what they have, and especially churches, including our cultures, is that they have neglected, or they've set this narrative to say if a child has an issue, always look within who might have done something wrong within the family… And in the way they isolate the family because while you are trying to understand the journey at the same time."*

Five out of the six participants experienced negative religious encounters. Some encounters are entrenched in cultural spirituality, while others stem from Christianity as a religious institution. Negative encounters included superstitious beliefs about the cause of the ID, expectations for divine healing, sins of the mother or father, blaming the parents for the disorder, demon possession and witchcraft. These findings affirm the understanding that disability is often interpreted through spirituality (Hanson, 2013:98). Participants find these experiences particularly upsetting as they place added guilt on them, make them suspicious of other family members, or imply that there is something bad about their child. Participants identify that they already have many feelings of self-blame, and beliefs regarding superstitious beliefs or sins of the father only fuel that blame. One participant explained that the pressure to address the spiritual issues is an added burden on her that her faith is not enough:

***P3**: "Because I remember when Jane was diagnosed, and a lot of people were telling me to pray. It was like, people are just saying pray because you might have done something wrong. It was as if you need to increase your faith so that she can heal."*

While religion and culture are often associated with a sense of belonging and support, participants expressed feeling more isolated, misunderstood, and alone due to their religious experiences (Masulani-Mwale et al., 2016:874). Interestingly, comparing ethnicity and religious experience, White participants' negative experiences primarily stem from a belief that CWID are demon-possessed. In contrast, African participants focus more intensely on the sins of the fathers or punishment by their ancestors.

Voices from the outside as a theme indicated that various systems within the persons eco system contribute to participants' isolation and loneliness. Although these systems

are located in the macro and exosystem of the persons' ecosystem and may seem far removed, they still impact the participants' MH (Teater, 2021:50). This theme highlights the fragility of extended family social, cultural and religious communities when faced with out-of-the-norm and differently-abled persons. Lack of education regarding ID, its impact on the child and its causes, lack of inclusive societies, and lack of understanding within communities and families are significant drivers for the stigmatisation and isolation participants' experience. The middle-income status of participants may make it easier for participants to isolate themselves from social structures and support as they are able to meet a considerable amount of their needs through access to paid resources and services.

4.2.2.5 Theme 5: Identity, Self-worth, roles, expectations and dreams of parents caring for children with intellectual disability

This theme focuses on the participants' sense of self, their perceived identity, roles and expectations they have of themselves. This theme was derived from the internal narratives' participants have regarding themselves, as it highlights the impact of caring for a CWID on the core beliefs held by participants. Core beliefs regarding self significantly impact how a person interacts with all systems within their ecosystem (Wearden, 2008:1247). Sub-themes represented under this theme are identity and self-worth, roles and expectations, and loss of dreams.

4.2.2.5.1 Sub-theme 5.1: Identity and self-worth

This sub-theme describes the impact that caring for a CWID, has on the participants' self-worth, self-image, identity and how they view themselves. The following interview quotes confirm this sub-theme:

> ***P1**: "…I feel like it's dealing with, like you're trying to balance everything, but you are not honest with yourself and you want to fix everything. You know, you're a mother and you feel like everything should be perfect and fixed and good. And you feel like, okay, so I can't fix my daughter. I can't fix my son. I can't fix the issues my husband's having. So now you're starting to think you're a failure… I don't feel good enough to be the person that everyone needs me to be."*
>
> ***P1**: "And that sort of just made me stop looking after myself again. Because I went, like, I'm not worth taking care of."*

***P3**: "You're feeling isolated all the time. And at the end of the day, that's why you then lose a sense of yourself because you don't have those moments where you have to care for yourself."*

***P6**: "Makes me feel like a bad mom that I've thrown my child away. But then I think, no, I've done the best for all for everyone. But then those thoughts keep coming back."*

***P6**: "And then I feel that I have failed and I have given up, I blame myself for her behaviour because I've given into her when she was small."*

***P3**: "You doubt yourself and say, okay, is actually this, is this actually the right decision for my daughter? Is it the right decision for my son?"*

The responses of participants indicate negative feelings about self and their identity. Participants recorded feelings of failure, being a bad mother, self-doubt, losing sense of self, and low self-esteem. Even in the face of rational thoughts and acknowledgement of the influence of negative narratives in society, participants struggle with negative thoughts about themselves. Hastings (2016:189) confirms this finding by articulating the negative impact of societal narratives on parents' self-image. Feelings of helplessness and a perceived lack of skills were highlighted as critical contributors to negative self-perception. Isa et al. (2016) emphasise the risk of increased anxiety and depression in parents with low self-esteem.

4.2.2.5.2 Sub-theme 5.2: Roles and expectations

This sub-theme represents the roles and role expectations participants perceive are expected of them and how caring for a CWID impacts their choices in the roles they wish to fulfil. The following interview quotes confirm the participants' perceptions of roles and expectations:

***P3**: "And I feel like that's the added pressure of being a parent who's raising a child who's neurodivergent is that people assume that we are these superheroes who have been chosen to take care of these kids and that we shouldn't feel anything, and that we should never be tired. And that our bodies should never take any kind of strain, physical strain, or mental or emotional strain. We just have to do what we have to do because our kids require us to do that, you know?"*

***P3**: "All we see are those superheroes that have been narrated. You don't see that mom who's breaking down. You don't see that mom who saying oh,*

actually today I wanted to take my life. It's not that I don't love my kids, but I was just tired."

***P4**: So I went to my usual doctor… Like I've been his patient for the longest time… So I thought he would be the best person to judge me because he knows that I have been the strongest person. I have never been an emotional wreck that I am."*

The data indicate that participants perceive that they have to play the role of a strong, competent parent who is emotionally stable and resilient. It is important to note in the participants' responses that much of the roles and expectations they assign to themselves are perceptions participants have of what others expect of them, rather than actual outside voices placing these expectations on them. This finding is corroborated by Cantwell et al. (2015:954), who found that perceived stigma, rather than verified stigmatisation, leads to negative self-assessment and low self-esteem.

The following quote illustrates how the caregiver's responsibilities impact the role choice of participants:

***P1**: "And you just sit there and go like, I work, I have to work. And now my kids, my daughter doesn't have any place to go. She doesn't fit in anyway. And you cry because do you stop working and you become just a mom? What is the impact of all of that?"*

Participants indicated that the caregiving needs of their children threatened roles they previously fulfilled. As primary caregivers, they have to make sacrifices to meet their children's and families' needs. Peer and Hillman (2014) highlight the change in roles, responsibilities, and sacrifices parents must make to accommodate the care needs of their CWID.

4.2.2.5.3 Sub-Theme 5.3: Loss of dreams

This sub-theme presents the loss of dreams participants experience, as confirmed in the following interview quotes:

***P3**: "And then it led me with a lot of emotions of shock, emotions of having to accept, but at the same time having to grieve that actually I'm not going to have a typically normal parenting journey."*

> ***P1**: "You just… there was like all of a sudden this whole bright picture was taken away, and I think it is because we have these hopes and dreams. You know. And we set ourselves up for that."*
>
> ***P5**: "So we struggled for quite some time. I wanted five kids but I got five in one at the end of the day."*
>
> ***P1**: "Realising that my daughter didn't care about how I react …"*
>
> ***P6**: "Our hopes were to have her at home and that it would work with our caregivers to have her where we could see that she's fine. And we really tried….So our hope was to have her as a normal family."*

Participants indicate that they experience a loss of hope and dreams for their children, their dreams of parenting and their preconceived ideas regarding bonds with their children. Graf (2018:179) asserts that parents' experiences of loss are tangible, and a process of adjusting their hopes and dreams are required for parents to regain equilibrium. In returning to the APA (2024b), it is important to focus on universal goals of parenting of ensuring the health and safety of children, growing productive citizens and transferring cultural values. The multidimensional loss expressed by participants is emphasised as many of their goals are not attainable for parents caring for CWID.

This theme links with theme three regarding caregiver burden, as the roles and expectations of caregivers can be so all-consuming that the parent experiences a loss of identity and loss of other roles when caring for a CWID (Griffith & Hastings, 2014:416). All elements uncovered in this theme threaten the participants' core beliefs regarding themselves and the world, threatening the mental well-being of participants if restructuring and changes in core beliefs do not occur (Wearden, 2008:1247). This theme confirms the notion of the ESP that a person and their environment are interdependent at all times (Teater, 2021:48).

4.2.2.6 Theme 6: Coping, resilience and support for parents

This theme was created from factors that the participants identified as positive factors that assist them in coping, adapting, accepting and thriving within the challenges of caring for a CWID. Sub-themes in this theme include finding ways to cope, support as a driver in resilience, acceptance, hope, and finding meaning in caring for a CWID, and positive factors of caring for a CWID.

4.2.2.6.1 Sub-theme 6.1: Finding ways to cope

This theme represents the elements participants identified as factors that assisted them in coping with caring for a CWID. Coping mechanisms are not defined as healthy and unhealthy coping mechanisms, but instead viewed from the participants' perspective as factors that assist them in coping. The following quotes confirm practical actions participants took in making it easier for them to care for CWID:

> ***P1**: "I basically decided that if I do go somewhere with my kids, I always make sure I have my caregiver with me…So I've learnt, I started to control the situation…"*
>
> ***P2**: "And so my me-time is generally always associated with whether I'm reading an article, listening to a podcast of parents that are on any topic that's related to disability. Or I'm watching a YouTube channel and that's like 35 or 30 minutes within my day … and it just makes me feel like okay. I'm not alone in this world."*
>
> ***P6**: "I've had to be on antidepressants to help me cope because I used to cry all the time. Yeah. So I've been on it for years and I won't stop because it's helped me. And I've started going to the gym. I feel better afterwards as well."*
>
> ***P3**: "So I've found that talking about it a lot helps. It's part of my coping mechanisms, I cry a lot, I write about it a lot just to share or write down my emotions because sometimes I might not be able to verbalise it, but if I write it down, it will just come through."*

Participants identify that self-education, setting up caregiver structures, being assertive regarding the needs of their children, exercise, crying, talking, journaling, and the use of antidepressants as strategies to help them cope better with the challenges. These coping strategies mentioned fall within managing internal or external goals and expectations or strategies to facilitate emotional regulation (Peer & Hillman, 2014:94).

The following interview quotes confirm awareness of the participant's own limits and emotional state as an essential factor in coping with caring for CWID:

> ***P5**: "And I'll be honest, if I say I can't look after her for 24 seven, I will just go crazy. My work is my escape."*
>
> ***P4**: "I get less frustrated when me, myself, I'm good. I'm in a better space."*

> ***P3**: "And it makes it a lonely journey, and at the same time, you then have, you start needing to go to a process where you need to push people away because now you have to build a boundary, you know."*
>
> ***P2**: "Because I really didn't want to get to a place of where I can't do anything for her because I know that she only has me. So I thought let me seek for help as soon as I can, before I start getting depressed because that's not gonna work."*
>
> ***P3**: "So one of the signs that I've noticed is that I become impatient, and I become impatient with Jane. And that's when I realised I'm like, okay, now it's coming, you know?"*

Participants indicated that awareness about their own MH, warning signs of MH distress, knowing their own limitations, and understanding the importance of seeking help early are factors that assist them in coping with caring for a CWID. Parents' well-developed emotional insight aligns with Boehm and Carter (2019:110), finding that insight and awareness play an important role in parents' emotional quality of life even in a relatively high-stress situation.

Three participants indicated the importance of emotional responsiveness from CWID as a factor in their MH, as seen in the interview quote below:

> ***P5**: But as things changed, and she changed, and she was at that point also, wasn't able to show me something. I was thinking to myself, there's nothing up there. And all of a sudden, it [responses from child] just came out.*

Participants indicated that the idea that their child would never be able to reciprocate any emotion or form an emotional connection with them was an overwhelming, hopeless idea for them. Once their children became older and were able to show some emotional awareness and create a relationship with the participant, participants experienced a turning point in their MH distress. These findings are confirmed by Mmangaliso and Lupuwana (2021:15) that a strong emotional relationship with the CWID plays a vital role in the parent's well-being.

The following interview quotes indicate the critical role of the participants' spiritual views in assisting them in coping:

> ***P6**: "I think crying to the Lord, praying, someone to cry to. Just giving me strength to cope every day. Where I just felt I couldn't cope anymore. But and*

then also, I go to ladies groups. And then I would ask them to pray for me, pray for Jane, because I was going through a very tough stage with her."

***P2**: "And the way that I deal with things is I always just say: Okay Jane was a gift from God and I just need to do the best. And I think that's also my drive for me. It's like yeah, and yes, what happened was very unfortunate, but God would have never allowed for her to be mine if He didn't think I was capable of doing the best for her."*

Participants express the important role of their spiritual beliefs in having a positive outlook on life, accepting their CWID, and finding the strength to face the challenges. Participants experience a sense of calling in their role as parents of a CWID, which makes the experience meaningful and important to them. Several studies have confirmed the importance of spirituality and own spiritual views in improving the quality of life and personal fulfilment experienced by parents caring for CWID (Boehm & Carter, 2019:100; Masulani-Mwale et al., 2016:872). The ESP framework views the chronosystem as a continuum of time (Teater, 2021:52). As participants progress in their journey of caring for a CWID and finding effective coping strategies, they develop increased resilience.

4.2.2.6.2 Sub-theme 6.2: Support as a contributor to resilience

This sub-theme presents the importance of support in the participants' ability to cope with challenges of caring for CWID. Formal and informal support from medical professionals, MH services, community, religious institutions, and extended family are included in this sub-theme.

The following interview quotes confirm the importance of informal support:

***P6**: "Or I'll just speak to my mom or my brother or my sister and say, this is what's happened."*

***P4**: "Now there are one of the people, one of the autism mothers who I drew strength from. She is my colleague as well. She said to me, look at the things that he can do rather than the things that he can't do…I think it's one of the strongest things that made me recover because I was a wreck."*

***P2**: "And I will definitely say that my greatest support here in Johannesburg would definitely be my sister."*

> ***P5**: "I think from a family perspective no my family… this little girl is loved in so many ways, she's the middle and the world is turning around her."*
>
> ***P1**: "And have a few friends that you can talk to. To have, I have at least two special needs moms that I can find. And each of them brings their own little version of how to look at things."*

The above interview quotes illustrate how participants find support from family, friends, and colleagues. Interestingly, most of the support the participants allude to, is emotional support. These findings support the articulation of Boehm and Carter (2019:100) that family and informal support structures are an important natural resource, protecting parents from significant distress.

The following interview quotes highlight the role of formal support structures for participants:

> ***P1**: "My children will be seeing the therapist here [Apricot Tree], because it makes my life easier. I can't drive around like a headless chicken anymore. And that is a big help."*
>
> ***P2**: "And yeah, definitely, the support from the therapists. Yeah, it's been like they have a personal touch that the doctors and paediatrician don't have. They definitely have a personal touch, they will sit with you. They will check on you…"*
>
> ***P2**: "So like I was saying going to Apricot Tree has been life-changing because definitely I don't feel alone. I always have another mommy that I can ask questions and it's like a small community that I never thought I would be part of. So definitely brings in that elements of: I have people that understand. And I have people that know how hard it can get."*
>
> ***P6**: "But and then also, I go to ladies group. And then I would ask them to pray for me, pray for Jane, because I was going through a very tough stage with her."*

Participants reflect on the positive contribution their care facility has made in their lives, as it educates and supports them in caring for their CWID. Other formal support, such as a ladies' group at church, also provides emotional support to participants. Isa et al. (2016:75) argue that the value of formal support is underestimated when considering the MH of parents caring for CWID and that knowledge, education, and resources regarding the disability and comorbidity mitigate parental distress.

4.2.2.6.3 Sub-theme 6.3: Statements of resilience

This sub-theme acknowledges the growth and resilience that surfaced in the interviews. During the interviews, it became apparent that each participant has had their own journey in caring for CWID and that each had experienced periods of maladaptive and adaptive functioning. The following interview quotes illustrate what resilience can look like:

> ***P3**: "It's just about my mindset what I feed into my mindset and that sometimes you know what it's okay to be not okay, you know. And just having those moments to say you know what Mrs F, today you feel like the world is just burning and everything is just tumbling down, and that's okay."*
>
> ***P3**: "I've got the opportunity to change that, and what about people that don't have that opportunity, how do I empower them to get that?"*
>
> ***P4**: "And then, for a mother who has already given birth and is somehow faced with this diagnosis, similar one, is that, yes, it's going to crush you. But what is important is for you not to be crushed forever. You need to be crushed, yes, but pick up yourself. Pick yourself up and seek help."*
>
> ***P4**: "I think, what makes my life better as a parent is to see his progress. I rejoice in the little things that I see him being able to do."*
>
> ***P5**: "I used to be facing a doctor. I was always afraid of bad news again. Now, whatever they tell me, they just have to be straight. I'm not going to crack down or something like that. So I think over the years, a lot of water went under the bridge."*
>
> ***P2**: "And so I think nothing at this point, I mean nothing can ever kill me. I've honestly gone through the worst with her and I've survived and so surviving each thing. I just think I can conquer everything. Nothing can stop it because I've gone…I've conquered very hard things…"*

These statements reflect the findings of Minnes et al. (2015:557) where parents who feel empowered in caring for their children demonstrate increased adaptability and resilience. These findings also support McConnell et al. (2014:2) who emphasise the role of positive adaptations as an essential factor in family well-being.

4.2.2.6.4 Sub-theme 6.4: Acceptance, finding hope and meaning in caring for a child with ID

Linked to the phases of diagnosis and living with an ID, as discussed in theme 1, the ideal phase would be acceptance and finding hope and meaning in caring for a CWID. In this sub-theme, the process of acceptance, how participants found meaning, and the presence of hope as elements of resilience are discussed. The following interview quotes illustrates this sub-theme:

> ***P3**: "I think for me those moments where just out of the blue, and she will come and just brush my face and then she smiles. Those moments for me I just think that I need to see, actually, I think, it's that you're doing a good job, you know. And it's more like you can't give up, you know. There is more to this purpose, you know. And one thing that my parents will always tell me, they would always say…sometimes God doesn't give you situations that you won't be able to handle. And it's something that I always remind myself to say you know what, I was chosen for specific reason, you know. I may not know that reason. I might not know what will happen in the next 10 years. But what I know now is that I have this life that I need to give in to, and to make it as beautiful as possible. And at the same time I feel that with everything and how I grew up, it's then that I need to take my experiences and build my own testimony because I don't want the next Mrs F to experience what I'm experiencing."*
>
> ***P3**: "I can cry about everything and feel like I don't have a chance to better my child's life, but at the same time while I'm crying, I'm actually realising that I've got an opportunity to change that."*
>
> ***P2**: I mean, like I said in the beginning I would say Okay God why me? and then that's okay. I can't actually ask why me because I wouldn't wish this on anyone else. And it had to be me because he trusted me with her and the only hope is God…"*
>
> ***P3**: "…if we can get to that level of understanding that God does not create mistakes, you know. God creates in order to teach as well and I'm taking Jane's life to say actually, like you said, she's building a testimony that people will one day take from her story and say if she's able to do this, you know, things like that."*

The above interview quotes confirm the meaning, purpose, and acceptance participants found in caring for CWID. Participants indicated how the sovereignty of God in their lives

has helped them to accept their child's diagnosis and has added meaning to their lives. Participants further suggested that they realise that they can help and support others in similar circumstances. Minnes et al. (2015:557) corroborate the importance of positive appraisal in coping with the daily responsibilities of caring for a CWID.

The following interview quotes confirm how participants have been able to find reasonable hope in response to the loss of dreams and ideals:

> ***P1**: "Yes, she's not achieving the goals that I would hope her to achieve, but she's happy. And that is, that's what keeps me going."*
>
> ***P3**: "I think for me it's also when I look at Jane's life if she is able to experience life in its fullness without her having to verbalise it…"*

The importance of finding hope are confirmed by the concept of reasonable hope as finding hope and meaning in the attainable rather than the unattainable (Weingarten, 2022:11).

Through varying responses, participants have confirmed the critical role of positive reframing and cognitive restructuring as an important element of resilience in parents, essentially restructuring core beliefs that better accommodate caring for CWID (Minnes et al., 2015:552).

4.2.2.6.5 Sub-Theme 6.5: Positive aspects of caring for a child with intellectual disability

The last sub-theme regarding coping and resilience presents the positive experiences parents have gained from caring for a CWID. Most participants indicated that they are thankful for how caring for CWID has changed them and the person they have become in the process, irrespective of the challenges they face. The following interview quotes represent this sub-theme:

> ***P6**: "I think it has. It's humbled me. It's put me down to earth. It's given me a heart for others, to have sympathy and love for others."*
>
> ***P1**: "You know, they have their way of communicating with you and just opening that whole new world of living in the moment. Living in the moment."*
>
> ***P3**: "I think the best part has been about realising that no matter how small an achievement is to celebrate it. I think we take a lot for granted. That little things that we are able to do for ourselves. And being Jane's mom has taught me so much about gratitude. It has taught me so much about being able to celebrate*

the wins no matter how small they are. It has taught me to be patient. It has taught me so much to be patient. But at the same time, it has also taught us as a family that different is beautiful. It has taught us that. And we just have to walk our journey in its fullness based on how we feel it and not based on what society or everyone tells us. So it has been a beautiful journey raising Jane."

***P5**: "I always say some parents just say go play outside. They've got no idea that playing for our kids is you playing with them. So then you spend so much more time with your children. I think that's sort of the appreciation of caring for her in this way, these little things in life that you see… For somebody its nothing but for you it's a wow and it's a almost a celebration on my side."*

Participants found that caring for CWID fosters humility, gratitude, patience, and love. They also felt that this experience has helped them to view the world differently and have a greater understanding of what is important. Kimura and Yamazaki (2019:218) and Masulani-Mwale et al. (2016:872), found that a greater appreciation for life and more meaningful relationships, sense of accomplishment, self-growth, tolerance, and deepening spirituality, as gains in caring for CWID. This concurs with Minnes et al. (2015:558), that a greater focus on the positive aspects of caring for a CWID, leads to better MH outcomes and a better quality of life for the parents and children. It is important to consider these perspectives in light of the biographical data, which indicate that none of the participants are struggling to meet their children's basic needs. This allows for a stronger drive towards self-actualisation (Trivedi & Mehta, 2019:39).

All sub-themes in this theme emphasise the various internal and external factors that play an important role in resilience in parents caring for CWID (McConnell et al., 2014:3, 12). Building resilience, finding acceptance and arriving at meaning, confirm the argument of Mazzucchelli et al. (2019:743), that parents value the positive change, that caring for a CWID offers them as individuals. This theme as a whole confirms (Boehm & Carter, 2019:110) argument that parents of CWID disagree with the societal view that disability is a tragedy but rather see it as different and positive. This theme emphasises the individuals' ability to adapt and change within their ecosystem, irrespective of the challenges within their ecosystem (Teater, 2021:49).

4.2.2.7 Theme 7: Services for parents caring for children with intellectual disability

This theme explores participants' experiences regarding services available for parents of CWID. As services for CWID are outside the scope of the study, emphasis will be placed on services for parents and not children. The sub-theme will include the gaps parents experience and the recommendations or wish lists they have for services.

4.2.2.7.1 Sub-theme 7.1: Gaps in services identified

This sub-theme focuses on the gaps in services, access and inclusion that participants experience.

> ***P3**: And obviously with people who would have seizures in townships, they would sometimes put a spoon in their mouth so that they don't bite their tongue. So, it's like it's all those things, yes. So, you find now that there's a disconnect where as much as we're trying to raise Jane, we now have to educate our parents. We have to educate our families*
>
> ***P1**: "I think the fact that, you know, if you have special needs kids, if you go, you sort of have to fight for parking. You have to fight for space. You have to justify why your child is in a wheelchair or in a pram when you go, for example, through access on the airport."*
>
> ***P2**: "So a lot of the society really just shy away and looks away and we don't want to look at it. It's not with our family. Let's keep it moving…"*

Participants express frustration regarding the lack of education about disabilities, outdated beliefs, lack of access, lack of inclusive public areas, and lack of inclusive communities, where persons with disabilities can feel accepted and safe. Interestingly, most frustrations are linked to societal mindsets rather than tangible services. When exploring deeper into the participants' frustration, it becomes evident that participants feel disconnected and marginalised within their communities (Kimura & Yamazaki, 2019:218). These experiences of participants contradict the aim of the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016) and SDG 10 (UN, 2024) which promote equality in access to services and human rights. Considering the economic situation of the participants in the biographical data, it is evident that the needs and gaps identified, reach beyond basic needs towards higher needs of self-actualisation, as illustrated in Maslow's hierarchy of needs (Trivedi & Mehta, 2019:39).

4.2.2.7.2 Sub-theme 7.2: Service recommendation

This sub-theme presents the recommendations participants made regarding services for parents of CWID. The question posed to participants was: What services do you feel will improve your quality of life as a parent caring for CWID? This sub-theme may be viewed as a wish list parents have. The practical needs of participants are reflected in the following interview quotes:

> ***P1**: "I feel if you had a place where you guys, where you and your kids can go, or a place where you can just go and feel normal. Where if we had to have a coffee shop, for instance, that was just for special needs. You know, like, no normal children around here. You know, that kind of thing where you can sit and have a coffee with another special needs parent and there's someone helping you."*
>
> ***P3**: "I know, for example, with the school with them wanting to build a respite centre for us, tt's coming across as a moment just for me to have time for herself."*

Participants had diverse suggestions regarding services or changes to improve their quality of life. Practical aspects include respite services and public spaces dedicated to persons with disabilities. The need for public spaces that cater for persons with disabilities has a latent theme of needing a place to belong and feel safe. Even though the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016) advocates and structures inclusive environments, participants' experiences of inclusive spaces contradict policy.

Participants express their need for MH services and parental support services in the following interview quotes:

> ***P6**: "I think they could have more homes for special needs, more support, more counselling where we could just go see a counsellor or speak to someone without costs involved."*
>
> ***P3**: "Therapy for moms is needed because there needs to be a level way, even if when they just talk about it, whether the therapy comes in certain resources in terms of for example how to handle burnout or even how to identify burnout, you know? Because for me therapy is not about just having to go to someone and just sit and I just talk about how I'm feeling."*

> ***P3**: "Yes, because what I've noticed is that in all the groups that we are there, we are operating at the same level. We are all caregivers, you know. Even if I might go and do research and say, okay guys today I just want us to talk about burnout and things like that, I'm still operating at a basic level because that's my only perspective in terms what I know. But I feel that in such setups for me, it would be important to have that one person who will not come from a caregiver perspective, but who will have that experience but then give us just a different, like a different view."*

During interviews, several participants expressed the importance of informal support groups, like WhatsApp and Facebook groups. However, participants indicated that these groups are limited in functionality, as they lack expert advice and input. Support groups with professional and peer collaboration were identified as a need. Adjacent to peer support groups and professional support, participants reported the need for psychoeducation services that will empower them as caregivers regarding their own MH and the care of their CWID. Masulani-Mwale et al. (2019:10) confirm parents' need for psychoeducation and formal support groups. The use of WhatsApp and Facebook groups as support systems highlights the importance of consideration of technology as a part of the techno system in the ESP as proposed by Navarro & Tudge, 2023:19339; Johnson & Puplampu, 2008:4).

Participants also communicated a lack of skilled MH counselling and the financial cost of counselling. Access to specialised and affordable MH services was identified as a recommendation regarding services focusing on parents. A study by Masulani-Mwale et al. (2016:876), confirms the lack of prioritisation and availability of MH services for parents caring for CWID in third-world countries. Kromberg et al. (2008:93) draw a connection between the lack of parental support services, specifically in South Africa, and poor MH outcomes for parents caring for CWID. The social worker's role as a counsellor is valuable in meeting the needs of parents (Hewitt et al., 2016:2119).

Lastly, the following interview quote recommends community education and fostering inclusive environments as a recommended service:

> ***P2**: "So yeah we need more awareness. We need people that also want to know and not to look at it, very far and to think Yeah, it's hard. Let's keep it moving."*

This recommendation is particularly important as practical recommendations and societal gaps mostly centred around the failure to create inclusive communities where

persons with ID and their families can feel safe and experience a sense of belonging. McKenzie et al. (2019:209) emphasise the lack of progress in creating inclusive communities and the need for patient and family participation in creating inclusive communities. The social worker's role as an advocate (Hewitt et al., 2016:2119) is essential in creating inclusive environments. This theme confirms the ESP principle that even systems distant from the individual, such as public policy and cultural norms and values, impact the functioning of the individual (Teater, 2021:51).

The above themes that immerged from the thematic analysis cover a wide range of factors that impact the MH of the participants. Some of the themes were clearly expected, based on the literature review, whereas other themes were more unexpected. The thematic analysis above indicates the effectiveness of this study to explore the authentic lived experiences of the participants. The thematic analysis answered the research question to understand the psychosocial factors that impact the MH of parents caring for CWID, while also meeting the goal of the study, by exploring psychosocial factors, resilience and services for parents caring for CWID.

4.3 SUMMARY

Chapter 4 presented the findings of the empirical study. Biographical information was presented according to information gathered and information important to the study. The findings of this study were presented in themes and sub-themes generated from the RTA of the data, seeking to understand the factors impacting the MH of parents caring for CWID. The seven themes included: the phases of diagnosis and caring for a CWID; implications of caring for a CWID for the family; caregiving experiences; voices from the outside; identity, self-worth, roles and expectations; coping, resilience, and support for parents; and services for parents caring for CWID.

Chapter 5 presents the key findings, conclusions and recommendations of the study.

CHAPTER 5
KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The previous chapter presented this study's findings by discussing themes and sub-themes that emerged from the data. This chapter will evaluate the study's effectiveness in reaching the research goals and objectives and how the research question was answered. This chapter will present key findings, conclusions, and recommendations, as well as the limitations of this study.

5.2 SUMMARY

5.2.1 Research goal

The goal of the study was: To explore the psychosocial factors affecting the mental health (MH) of parents caring for children with intellectual disabilities (CWID) in Benoni, Gauteng. This goal was reached through focused objectives, scientific research methodology, a sound theoretical framework, a literature review, and an empirical research study.

5.2.2 Objectives of the study

Each objective will be evaluated in terms of how it was met through this study.

5.2.2.1 Objective 1

To explore the psychosocial factors that contribute to the mental health of parents caring for CWID in Benoni.

The researcher conducted an immersive review of the literature to explore the phenomenon of caring for a CWID and its impact on the MH of parents. The information was organised into a comprehensive literature review, including aspects such as intellectual disability, caregiving challenges, and factors influencing parenting and parenting CWID (sections 2.2 and 2.3). Additionally, literature on the psychosocial factors affecting the MH of parents caring for CWID (section 2.5) was explored and presented, indicating that family dynamics, social support, culture and religion, stigmatisation, access to services and the burden of being a caregiver for a CWID

significantly impact the MH of parents. During data collection, the researchers asked participants about their personal experiences of caring for a CWID, and how various psychosocial factors impacted their MH (section 4.3).

Empirical findings mostly concurred with the findings of the literature review. However, the study found that individual characteristics and challenges of the disability, significantly impact the caregiver burden and MH of the parent. Within this study, it was further found that the lack of support in the microsystem, such as family and social connections, is more significant in impacting the MH of participants, than the lack of access to services and support from larger structures.

The ESP as a theoretical framework guided the researcher in understanding the interaction of various systems within the parents' lives, ultimately impacting their MH. The biographical data strongly indicated that participants were middle-class families that could mitigate the challenges in the exo- and macrosystems. Still, challenges experienced in the microsystem were not mitigated by their economic status.

5.2.2.2 Objective 2

To identify parents' coping strategies to manage the stress associated with caring for their children in Benoni.

An in-depth understanding of what MH is (section 2.4), the adaptation (section 2.5.2) and parental coping strategies (section 2.6.1.1) was gained and presented in the literature review. The literature review revealed that adaptation strategies within the family, spiritual beliefs, reframing and finding a reasonable hope, and access to informal support, are factors that assist parents in coping with the challenges of caring for CWID. The empirical data confirmed these findings. Although many of these coping strategies lie within the individual, supportive structures in the micro-, exo- and macrosystems provide equilibrium for the parent to be flexible and adaptable to their circumstances, finding meaningful coping strategies.

5.2.2.3 Objective 3

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

A review of current literature regarding the nature of social support and the impact thereof on the MH of parents caring for CWID revealed two diverting aspects.

International literature emphasised the critical role of formal social support, while literature based on African and South African studies emphasised the importance of informal social support for parents. Both perspectives were considered during the literature review (section 2.5.3), as the demographics of the sample population are more congruent with Western standards of living than most populations in Africa, and 50% of the participants were Africans and 50% were White. The empirical findings of this study indicated a significant preference for informal support and its role as a protective factor in parents' MH. This informal support includes family members, friends, and persons within the disability community. Outside of the services offered by the Apricot Tree Centre, participants used few formal social supports.

5.2.2.4 Objective 4

To describe the role of resilience in promoting the mental health of parents caring for CWID in Benoni.

Resilience and coping mechanisms are intertwined with one another. The researcher familiarised herself with the concept of resilience, factors contributing to human resilience, and resilience in parents caring for CWID. The literature review explored and presented factors such as reframing, acceptance, reasonable hope, making meaning, and the role of support (section 2.6). Support and economic stability were highlighted in the literature as important protective factors of resilience.

During data collection, questions regarding coping and adjustment focused on exploring resilience, as resilience is often poorly understood in everyday language. Furthermore, during data analysis, statements of resilience and latent coding were used to capture the resilience in participants.

The study's findings confirmed that mental shifts such as reframing, reassessing values and norms, and redefining meaning, play an important role in resilience (section 4.3.6). However, disequilibrium and emotional distress threaten a parent's ability to remain resilient (sections 4.3.1 and 4.3.3).

5.2.2.5 Objective 5

To suggest recommendations for improving the services provided to parents caring for CWID.

This objective was achieved through gaining an understanding of services available for parents caring for CWID, a literature review of services, and the empirical research. Literature highlighted that services for CWID are often geared towards the child only, and they compensate for the challenges the child experiences; little emphasis is placed on services for parents and families of CWID (section 2.7). Literature confirmed the vital role of psychosocial services for families, the importance of a multidisciplinary approach and the role of social work in advocacy, education, counselling and case management section 2.7.1).

The empirical research confirmed the lack of government services for persons with ID and their families and emphasised the financial burden of parents to access the needed services (section 4.2.7). As most participants were financially able to meet the care needs of their CWID, the findings focused on the need for specialised MH services for parents and the need for the formation of inclusive societies that are open and accepting to differently-abled persons. General MH services and counselling are not able to offer adequate intervention and support to parents, highlighting the need for specialist services within the multidisciplinary team offering services to the family as a whole.

5.2.3 Research question

The study answered the following research question:

- What are the psychosocial factors affecting the mental health of parents caring for children with ID in Benoni, Gauteng?

The research question was answered through a qualitative study using six one-on-one interviews with participants. The questions in the semi-structured interview schedule guided the interview and aimed to answer the research question and gain data on the participants' personal experience of psychosocial factors impacting their MH. The data was analysed through RTA, and seven themes with sub-themes were generated in response to the research question. The themes and sub-themes are presented in detail in Chapter 4.

5.3 KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

The conclusions regarding the research methodology, the theoretical framework and literature review are firstly provided. Thereafter, the conclusions and recommendations

of the biographical findings are provided, followed by the key findings, conclusions and recommendations of the thematic analysis as outlined in Table 4.2 in Chapter 4.

5.3.1 Conclusions from the research methodology

While qualitative research limits the generalisation of findings, it provided a deepened understanding of parents of CWID, which is valuable for organisations and professionals working in the helping professions, to help them better understand the challenges parents of CWID face and tailor services to meet their needs. This confirms that applied research was the most suitable type of research for this study.

Using semi-structured interviews and an interview schedule (Appendix 7), proved to be an effective approach, as it allowed the researcher to stay focused on the research question while simultaneously building rapport with participants. This approach encouraged participants to share their experiences as parents of CWID freely and openly. As the study aimed to explore the parent's experience rather than testing a hypothesis, the semi-structured interview allowed the data to be analysed inductively.

The recorded interviews allowed the researcher to compile accurate verbatim transcripts. As the sample population was small, the researcher opted to personally transcribe the data with the assistance of a transcription tool, namely, Turboscribe. This was the first step in immersion in data for data analysis purposes. RTA as a data analysis method allowed for a structured data analysis that allowed inductive 'wrestling' with the data, allowing themes to emerge from the data rather than attempting to confirm preconceived themes. An inductive approach challenged the researcher to assess themes critically and interpret the themes in relation to the ESP as a theoretical framework.

The study's trustworthiness was upheld throughout, with strategies such as member checking, sound methodology and theoretical framework, reflexivity and meticulous recordkeeping. Ethical considerations were prioritised during the study to uphold confidentiality, the participant's rights, and the debriefing of participants.

In conclusion, the planned research methodology was appropriate for this study, with little to no deviation from the proposed methodology.

5.3.2 Conclusion from the theoretical framework and literature review

The ecosystems perspective (ESP) was used as a theoretical framework for this study. As the ESP view the parent caring for a CWID within its environment and not in isolation. The ESP assisted the researcher in interpreting the factors impacting the MH within the ecosystem of the participants and created awareness of the interactive nature of all aspects of these parents' lives. No element within the system, nor the individual, can be viewed in isolation, but should be assessed within the context of the entire system. In congruence with the order in the ESP, the study found that the psychosocial factors within the micro and mesosystem of the parents' ecosystem, have the most significant impact on their MH. Factors that are further removed for the parent are more likely to impact the parent's well-being indirectly. The ESP safeguarded the researcher from interpreting the data out of context, ensuring the study's credibility. It can be concluded that the ESP was an effective and applicable theoretical framework to underpin this study, also used in answering the research question.

The literature review provided knowledge that indicated that ID is significantly prevalent in society, although seldom seen. Normal parenting challenges are exasperated by additional ID-related challenges for parents caring for CWID. The literature review expounded on the fragility of MH and the natural process of adaptation and maladaptation across the lifespan, emphasising risk factors for poor MH outcomes. This framework helped the researcher explore factors beyond typical parenting challenges that impact the MH of parents caring for CWID. A review of psychological factors such as emotional responses, burnout, coping, and resilience assisted the researcher in understanding the impact of these factors on the parents' MH. Social factors such as support, cultural views, family dynamics, religion and spirituality, and stigmatisation clarified the constructed world of parents caring for CWID. Socioeconomic factors such as access to services and economic burden highlighted the macrosystem impact on the parents. All these factors constructed a clear picture of the psychosocial factors impacting parents caring for CWID.

Understanding the challenges parents face caring for CWID allowed the exploration of coping and resilience in these parents. The literature review seeked to understand factors contributing to good MH outcomes for these parents, such as finding hope and meaning, spirituality, empowerment, and support. Furthermore, the review determines

factors threatening good MH outcomes, such as behavioural and sleep challenges, lack of support and caregiver burnout.

Finally, a review was conducted on the services available to parents of CWID and the role of social workers in addressing the needs of these parents.

It can be concluded that a variety of psychosocial factors impact the MH of parents caring for CWID. Still, all these factors have to be viewed with interconnectedness and in relation to each other, as posed by the ESP to answer the research question successfully. In conclusion, the literature review was beneficial, relevant and appropriate to the study and research question.

5.3.3 Conclusions and recommendations on the biographical data

In conclusion to the biographical data presented, all participants play the role of primary caregiver for their children, offering an in-depth understanding of the roles and responsibilities of caregivers of CWID. One participant placed her child in a full-time care facility, approximately a month before the interview. All participants represent middle-class families with access to paid resources and do not rely on free resources provided by the state. Participants have access to various forms of formal and informal support.

This study should be viewed in the context of middle-income families within South Africa, from different ethnicities who generally have considerable access to resources. Other findings that form part of the larger MSW Healthcare 2023 group study should be considered to gain a holistic image of parents caring for CWID within the South African context across living standards.

Subsequently, each theme, together with its conclusions and recommendations, is presented.

5.3.4 Key findings, conclusions and recommendations on the thematic analysis

5.3.4.1 Theme 1: Phases of diagnosis and caring for a child with intellectual disability

This theme focused on the different phases from pre-diagnosis to living with and caring for a CWID, as experienced by the participants.

5.3.4.1.1 Key findings

All participants' experience of 'outside of normal' behaviour and challenges with their CWID started before diagnosis. Participants' children were generally born as healthy, normal children, but they soon realised abnormalities in failure to thrive, excessive crying, sleeping problems, and failure to meet developmental milestones. Participants already experienced this phase as lonely, as they were criticised for being overly concerned about their children.

Once they did seek help for their child, the process of diagnosis varied greatly, from same-day diagnosis, to children that remain undiagnosed for years. Participants expressed various initial emotional responses to the diagnosis, such as shock, grief, anger, and denial. These emotions described by participants are common and serve as a crucial part of processing a CWID diagnosis. In the presence of these responses, participants also felt relieved and calmed by a diagnosis, as it answered some of their questions and ended their uncertainty and parental guilt.

Participants experienced a range of emotions towards parenting a CWID in the years since the diagnosis, including anger, shame, depression, and anxiety, with some even reporting suicidal thoughts. These emotional responses were universal across all the participants, regardless of age or ethnicity, and were often overwhelming. These emotional responses are essential aspects of long-term MH well-being. It is clear that systemic factors within their environments influenced their emotional responses.

5.3.4.1.2 Conclusions

The findings of this study emphasise the varying emotional responses in parents of different ethnicities caring for CWID, according to personal experience, previous trauma, and phases in the lifespan of caring for a CWID. An important finding was the participants' lack of support experienced even before diagnosis, which is a clear narrative throughout their experience of caring for CWID.

5.3.4.1.3 Recommendations

From this theme the researcher recommends the following:

- Greater awareness and support to parents with concerns about the development of their children at an early age.

- The development of further knowledge regarding the various phases of parenting a CWID, and the adaptation of services to incorporate this knowledge.

5.3.4.2 Theme 2: The implications of caring for a child with intellectual disabilities for the nuclear family

This theme reflects how caring for a CWID impacts the nuclear family, including siblings and parents, and the marital relationship of parents.

5.3.4.2.1 Key findings

The family composition of each participant varied. However, the consensus in the findings is that caring for a CWID impacts all aspects of the family. Participants with other children experience guilt and anxiety about time, finances and energy distribution of resources within the family, feeling that other children are neglected. The caregiver burden negatively impacts the participants' ability to parent and connect with all their children. Although most participants indicated that they have experienced maladaptation within the family, the participants who struggle the most with finding equilibrium in their family are those whose CWID have behavioural challenges.

Interestingly, although most literature emphasises the negative impact caring for a CWID has on marital relationships, participants acknowledge the challenges they experience within their marriage, but place greater emphasis on the support structure their partnership offers them.

Participants indicated that caring for a CWID limits the family's leisure time and activities and access to social support and engagement in social activities. These limitations are significant to note, as lack of social engagement and support are a risk factor for poor MH outcomes for parents. Still, a child's disability often limits the family's ability to engage in such support structures, leading to a conundrum. This goes hand in hand with the trade-offs families need to make to meet the needs of their CWID, such as working away from home, working overtime, and moving away from support systems to access better services. The participants carefully considered these trade-offs but again focused on the needs of the CWID, leaving other family members vulnerable.

The impact of caring for a CWID was not all negative for the participants. Participants found that the sense of belonging in dealing with challenges and the personal attributes

such as compassion and lack of prejudice gained by all family members, mitigated some of the challenges of caring for a CWID.

5.3.4.2.2 Conclusions

Hanson (2013:101) correctly asserted that caring for a CWID has a rippling effect throughout the family, requiring stress and adaptation on a continuum of phases. Parenting a CWID poses challenges, but so does parenting other children in a household with a CWID. The difficulties in care pose challenges, limitations, and forced trade-offs for all family members. Participants' resilience in forming support structures within the nuclear family is important in understanding ways to facilitate better-than-expected outcomes for families with CWID.

5.3.4.2.3 Recommendations

The following recommendations are derived from this theme:

- Early intervention for CWID should focus not only on the child, but also on the child's family, mitigating the formation of maladaptive behavioural patterns and securing a safe and stable environment for all family members.
- More inclusive communities and greater access to resources to address the limitations families experience and the detrimental trade-offs they have to make to accommodate the needs of CWID.

5.3.4.3 Theme 3: Caregiving experiences

This theme represents the experience of parents as caregivers, the demands on them as caregivers, the challenges they experience, their experience of precipitating factors leading to caregiver burnout, challenges related to medical needs, and behavioural and sleep problems.

5.3.4.3.1 Key findings

The caregiver burden requires the participant to balance an array of emotional challenges, such as anxiety and exhaustion, while fearing to leave their CWID with other people, leading to a continuous sense of hypervigilance, again exasperating exhaustion. The all-consuming nature of being the primary caregiver for a CWID, leads to feelings of being overwhelmed, alone, and the loss of parental identity. The

participant's realisation that their well-being determines the child's well-being, is viewed as a negative aspect, as it adds additional burden and distress on the participant.

Participants experience significant distress and anxiety regarding medical needs, such as seizures and hospitalisation of CWID.

Furthermore, individual characteristics of CWID, such as being non-verbal, having sleep disturbances or behavioural challenges, significantly impacts the quality of the relationship with the child and the MH of the parent. Sleep disturbances in CWID are identified as one of the significant factors preceding a MH crisis in the participants. Participants in the interviews reported that their MH is heavily impacted by the behavioural challenges of a CWID, leading to feelings of self-blame, isolation, emotional distress, and fear for safety. These challenges limit families' ability to engage socially and find adequate care support. Contrary to the literature, participants attribute behavioural issues to poor parenting, leading to greater psychological distress in participants and poor self-esteem.

5.3.4.3.2 Conclusions

Exhaustion caused by caregiver responsibilities of parents caring for CWID significantly impacts the participant's ability to cope and adjust to challenges, negatively impacting the MH of the participants. In a cycle of isolation, isolation leads to anxiety and hypervigilance in participants, in turn leading to exhaustion, which negatively impacts the parent's ability to use support structures, exasperating the isolation experienced by participants. Loss of parental identity, at the cost of caregiver identity was identified as a factor that impacts the quality of life of parents and the relationship between parent and child. Behavioural and sleep disturbances significantly exasperate the daily challenges and MH challenges experienced by participants.

This theme underscores the interaction (mesosystem) between the individual and microsystem, the impact of dysfunction within the larger systems on the participants, and the direct demands on the participant's MH. The lack of support in the exo- and macrosystems magnifies the demands from the microsystem.

5.3.4.3.3 Recommendations:

The following recommendations were derived from this theme:

- Psychoeducation regarding caregiving challenges, support, and boundaries will assist parents in balancing caregiving demands with other demands on parents and self-care.
- Trained respite care will alleviate caregiver burden on parents caring for CWID.
- Greater awareness regarding the psychosocial impact of behavioural challenges in CWID among professionals supporting parents, is essential in tailoring support for these parents.

5.3.4.4 Theme 4: Voices from the outside

This theme represents the beliefs, perceptions and behaviour of various systems outside the participants' nuclear family in response to CWID. This theme describes the participants' experience and response to external opinions and views, and how it impacts the MH of the parents caring for CWID.

5.3.4.4.1 Key findings

Participants indicated that extended family dynamics often cause stress and conflict, as relatives frequently have strong opinions on how to handle their child's diagnosis, finances, and treatment. These opinions frequently conflict with medical advice and the parents' own goals. Especially in African families, the views and opinions of the extended family caused marital tensions and discord. Participants further report a disconnect between the support desired from the family and the actual support offered, stemming from the family's lack of understanding of ID and cultural norms.

Participants identified that social and community views on ID negatively impact their social interactions. Lack of awareness of disabilities and lack of inclusive societies, make participants uncomfortable taking their CWID into public spaces. The data revealed a common theme that participants find pity offensive and as a form of stigmatisation. The societal view that disability is a tragic occurrence clashes with the participant's lived experience of caring for a CWID. Participants experienced a lack of understanding within their social support networks of their caregiving burden, leading to feelings of isolation and loss of support.

Most participants had negative religious encounters, stemming either from cultural spirituality or Christian beliefs that involve superstitions about the causes of ID, divine punishment, demon possession, or witchcraft. These experiences contribute to feelings of guilt and self-blame. While religion typically offers support, participants felt more isolated and misunderstood, with White participants encountering beliefs about demon possession. In contrast, African participants faced notions of ancestral punishment or sins of the fathers as the cause of ID.

5.3.4.4.2 Conclusions

This theme highlights how dysfunction in various systems within participants' ecosystems contributes to their isolation and loneliness, even those seemingly distant in the macro- and exosystems. The lack of support and source of distress within the extended family was a surprising finding. A lack of education about ID, inclusive societies, and understanding within families and communities are critical drivers of the stigma and isolation experienced by participants.

5.3.4.4.3 Recommendations

The following recommendations were derived from this theme:

- Addressing stigmatisation will impact the level of support participants experience, not only in the wider society, but also in their close connections.
- Greater effort in including emotional awareness and empathy in early education can create emotionally agile societies, addressing matters such as well-intended, but poorly executed pity.

5.3.4.5 Theme 5: Identity, self-worth, roles, expectations and dreams of parents caring for children with intellectual disability

This theme focuses on the participants' sense of self, their perceived identity, roles, and expectations of themselves.

5.3.4.5.1 Key findings

Perceived failure to meet the demands of caring for a CWID, negatively impacts the self-esteem and identity of the participants. Participants experienced feelings of failure, low self-esteem, and self-doubt. Participants struggle with negative thoughts about

themselves despite rational awareness of society's harmful narratives and its impact on their self-image.

Participants experience expectations to be strong, competent, and emotionally stable parents, though these expectations often stem from their own perceptions of what others expect rather than actual outside pressures. This highlights that perceived stigma and self-stigmatisation as factors impacting the MH of parents caring for CWID.

Participants experienced a loss of hope and dreams for their children, parenting expectations, life goals, and envisioned bond with their child. Loss of parental hopes and dreams was significant, as many of their parenting goals, such as the health and safety of their children, fostering independence and the transference of cultural values, are unattainable when caring for CWID.

5.3.4.5.2 Conclusions

The challenges participants face reach beyond typical parenting challenges, testing their ability to cope and adapt, often leaving them with feelings of failure and causing them to question their own abilities, ideals, and dreams. Loss of personal hopes and dreams and discrepancies in identity, self-worth and expectations bring about a misalignment in core beliefs. Positive adaptation requires restructuring and reframing of core beliefs. In light of the ESP, the participant's perception regarding the micro and exosystem, irrespective of the reality within the system, impacts the participants' sense of self.

5.3.4.5.3 Recommendations

The following recommendations were derived from this theme:

- MH services focusing on addressing the MH needs of parents caring for CWID should attend to the strengthening of self-esteem, core beliefs about self and roles and expectations of themselves to ensure emotionally agile parents who experience quality of life and resilience in caring for CWID.
- Continuous adaptation within the parents' MH is required for the formation of resilient families caring for CWID.

5.3.4.6 Theme 6: Coping, resilience and support for parents

This theme focuses on the factors impacting the participants' ability to cope and adjust to the challenges they face, factors that contribute to resilience and MH in participants and how support impacts the resilience of participants.

5.3.4.6.1 Key findings

Participants use various coping strategies, including self-education; establishing caregiver structures; assertiveness about their children's needs; antidepressants; exercise; and emotional outlets like crying, talking, journaling; to manage both internal and external expectations and support emotional regulation. Emotional awareness and skills to self-regulate, assist participants to cope with the challenges of caring for a CWID and contribute to good MH outcomes for the participants.

Emotional development in the CWID, although different from that in their peers, assists parents in finding greater meaning in caring for their children. The ability to develop an emotional bond with their children mitigates caregiving challenges.

Participants highlight the importance of their spiritual beliefs in developing a positive outlook, accepting their CWID, and finding a sense of calling that brings meaning and fulfilment to their parenting experience.

Participants indicate that social support plays a vital role in their ability to cope and adapt to their challenges. Emotional support was highlighted as the most fundamental support. Although family and society often fail to meet the participants' needs, they have been able to build supportive structures in these challenging environments.

Statements of resilience reflected a sense of empowerment, finding meaning in their challenges, accepting the CWID as they are and finding a hope that aligns with their limitations. For many participants, this hope and meaning is found in spiritual beliefs and reflecting on their journey as parents of a CWID.

Participants reported that caring for CWID fostered humility, gratitude, and patience, changing their perceptions of the important matters in life. Participants reported personal growth, more meaningful relationships, and a sense of accomplishment, contributing to better MH and quality of life.

5.3.4.6.2 Conclusions

The theme emphasises the role of internal and external factors in building resilience, with parents often viewing disability not as a tragedy, but as a source of positive change and deeper meaning.

5.3.4.6.3 Recommendations

The following recommendations were derived from this theme:

- Shifting attitudes in society regarding persons with ID and the inherent worth of people, will strengthen support and in turn, foster resilience in parents caring for CWID.
- Professionals providing MH services to families with CWID, should focus on understanding the factors that assist each individual in building resilience and making meaning of their circumstances, building on those aspects to strengthen resilience in parents caring for CWID. These factors are deeply individualised.

5.3.4.7 Theme 7: Services for parents caring for children with intellectual disability

This theme presents the participants' experience of services available to parents caring for CWID. The theme includes the gaps participants experience and the recommendations the participants presented.

5.3.4.7.1 Key findings

Similar to broader society, participants had difficulty distinguishing between services for CWID and services for parents caring for CWID. A significant theme identified was the lack of inclusive and accessible public domains and the absence of inclusive attitudes. Participants expressed that even though policy and legislation such as Mental Health Care Act 17 of 2002 (Republic of South Africa, 2002), SDG 10 (UN, 2024) and the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016), advocate inclusive societies and equality, they experience general unease in public. Interestingly, most frustrations are linked to societal mindsets, rather than tangible services.

In line with the gaps identified, participants recommend creating public spaces for the disabled, by the disabled, where they can feel comfortable.

Regarding MH services, although the participants all had access to counselling and support services, some chose not to use those services, and others who used the services felt that they did not meet their needs. Professionals were not proficient in addressing their challenges. Participants also underscored the value of informal support groups, but identified that the lack of professional knowledge in support groups limits the effectiveness of the groups.

5.3.4.7.2 Conclusions

Considering the economic situation of the participants in the biographical data, it is evident that the needs and gaps identified, reach beyond basic needs towards higher needs of self-actualisation, as illustrated in Maslow's hierarchy of needs. Excluding the lack of sufficient MH services, the gaps in services, and service needs identified by the participants centred around the macro system failure in societal attitudes, mindsets, policy, and accessibility.

5.3.4.7.3 Recommendations

The following recommendations are made regarding this theme:

- Acknowledging the macro system failures, in creating inclusive communities where families with ID feel they can belong is essential in facilitating change. Such change is only possible through including and engaging marginalised communities in the mind shift.
- These findings challenge the consensus that all MH services are equal. Caring for a CWID and other disabilities is a complex task that needs specialised support and intervention. MH professionals trained in this field must deliver effective services and interventions to parents caring for CWID.

5.4 RECOMMENDATIONS FOR FUTURE RESEARCH

The following recommendations for future research emerged from this study:

- Research findings indicate an essential connection between parental MH, behavioural challenges of CWID, and social support. Further research into the role of behavioural challenges in social isolation and lack of informal social support can be investigated. Future research could explore how behavioural

challenges contribute to isolation and a lack of informal social support for parents.

- The research highlighted the onset of isolation and lack of support long before an ID has been diagnosed. Future research can explore the impact of early psychosocial intervention for parents and the long-term impact on coping and resilience of parents caring for CWID.
- At the dawn of establishing technology as part of the ESP, advancements in this area will significantly impact research in the future when concretely integrated into theory. Research into the impact of access to information on the MH of parents caring for CWID will be important in understanding parental experiences and utilising technology for service delivery.
- Research into the specialisation of MH services and support services that meets the needs of families of CWID.
- Future research on the potential role of social workers in direct and indirect roles in the field of persons with disability, will assist in guiding and solidifying their role in this field.

5.5 LIMITATIONS OF THE STUDY

The following limitations of the study were identified:

- **Generalisation of findings:** This study was conducted within a small homogenous population in Benoni, Gauteng, consisting of multicultural middle-income participants with good access to services and medical care. The findings cannot be generalised to poorer populations with significantly reduced access to services.
- **Variables:** The emotional well-being of the participants on the particular day of the interview could have impacted the participant's articulation of their experience of caring for a CWID in that particular day. As seen from the data, caring for a CWID can be an emotional rollercoaster, and the emotional state of each participant on the day of the interview can also impact the data. The fact that only one interview was conducted with each participant does not accommodate such fluctuations.
- **Various diagnoses in CWID:** The various diagnoses of each participant's CWID can impact the homogenous nature of the participants, as each diagnosis

has its own unique challenges. The similarity of severity countered this, but can be viewed as a limitation of the study.

5.6 FINAL CONCLUDING REMARKS

The MH of parents caring for CWID is affected by a range of psychosocial factors, from personal internal challenges to broader influences within the macro system. The challenges posed by caring for a CWID cannot be managed and overcome by an individual alone, but require outside support. The interconnectedness of parental well-being with the well-being of the child, advocates for a move away from services and support focused on the CWID to services and support for the family unit. Social workers can play an important part in services that promote the well-being of the CWID and the family.

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APPENDICES

Appendix 1: Request for permission to perform study at Apricot Tree Centre

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Dept. of Social Work & Criminology

Humanities 100. Since 1919

01/04/2024

Ref. Lindie Bull Student Nr. 23253674
Tel. 0845002256
E-mail: lindie.bull@tuks.co.za

The Principal
Apricot Tree
10 Ninth Ave
Northmead

Dear Madam/Sir

REQUEST FOR PERMISSION TO CONDUCT EMPIRICAL RESEARCH AT YOUR ORGANISATION: APRICOT TREE BY MSW(HEALTHCARE) STUDENT - LINDIE BULL (23253674)

Lindie Bull is a registered postgraduate student for the **Master of Social Work (Healthcare)** degree programme in the Department of Social Work and Criminology, University of Pretoria.

One of the requirements is to conduct research and write a mini-dissertation, resulting from a research project, under the supervision of an appointed supervisor, namely Prof C.L. Carbonatto. The research will only proceed once a departmental Review Panel and the Faculty of Humanities Research Ethics Committee have approved the research proposal and data collection instrument(s). The following information from the research proposal is shared with you, although a copy will be provided to you if needed:

The envisaged **title** of the study is: Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities.

The goal of the study is: To explore the psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng.

The objectives of the study are:

Room 10-10, Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 4202410
Email: Charlene.carbonatto@up.ac.za | www.up.ac.za

- To describe the psychosocial factors that contribute to the mental health of parents caring for children with intellectual disabilities.
- To explore the psychosocial factors that contribute to the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng.
- To identify the coping strategies that parents use to manage the stress associated with caring for their children with intellectual disabilities in Benoni, Gauteng.
- To understand the sources of social support that parents receive and how it impacts their mental health.
- To describe the role of resilience in promoting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng.
- To suggest recommendations for improving the services provided to parents caring for children with intellectual disabilities.

The envisaged target group of the study is: Parents of children with intellectual disabilities.

The empirical part of the study will entail conducting personal interviews with the parents of the children with intellectual disabilities, using an interview schedule and voice recording of the interview with the permission of the participants for data collection purposes. All information will be dealt with confidentially, their identity will be protected and ethical considerations will be abided to.

This request will require practical assistance from your staff in sharing the details of this study with parents as potential participants, using an information letter. If any of the parents are interested in partaking voluntarily, they will be asked to provide you with their contact details. The researcher will collect these details from your organisation, in order to contact the potential participants. Participants who agree to partake will be required to sign an informed consent form before an appointment for the interview is arranged with them.

No costs will be incurred by your organisation with this request.

Possible benefits for your organization can be summarised as follows:

- The study will help professionals to better understand the unique psychosocial factors impacting the parents of children with intellectual disabilities within the South African context.
- The study can assist Apricot Tree in determining the needs of parents of children with intellectual disabilities benefiting from their services.
- The study will help Apricot Tree to tailor services for parents of children with intellectual disabilities.

A copy of the final research report results will be made available to your organisation after completion.

It would be appreciated if you could please consider the above request favourably, and grant permission on a letter with a formal letterhead to proceed with the project, at your earliest convenient date.

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Yours sincerely,

Lindie Bull
Researcher

Prof CL Carbonatto
Supervisor

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Appendix 2: Permission for empirical study from Apricot Tree Centre

apricot tree
CENTRE FOR STIMULATION AND DEVELOPMENT
Reg. No. IT2337/12 - PBO. No. 930 042 188 - NPO. No. 125-788 NPO

11 9th Avenue Northmead Benoni
Contact: 011-849 0330
E-mail: info@apricottree.co.za
ATD 20

Dear Lindie Bull

11 April 2024

Re: Research study permission request

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

Apricot Tree Centre: a Centre for stimulation and development hereby grants permission for you to conduct the abovementioned research study at 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 Apricot Tree 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,

A Jreason

Abby-Jade Reason

Principal

Appendix 3: Approval from Ethics Committee, University of Pretoria

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

03 July 2024

Dear Ms L Bull

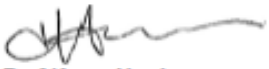
Project Title:	Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities
Researcher:	Ms L Bull
Supervisor(s):	Prof CL Carbonatto
Department:	Social Work and Criminology
Reference number:	23253674 (HUM001/0524)
Degree:	Masters

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

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Appendix 4: Participant Information Sheet

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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Dept. of Social Work & Criminology

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PARTICIPANT INFORMATION SHEET

Title of study: Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng

Dear Participant,

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

As a parent caring for a child with an intellectual disability, you have been approached by the gatekeeper of the organisation Apricot Tree, Mrs. Abby-Jade Reason, as a potential participant, in the abovementioned research study. Thank you for your time in considering 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. Lindie Bull, the researcher, who will be conducting the interview with you, is a qualified social worker, registered with the South African Council for Social Services Professions (SACSSP). An interview guide will be used to guide the interview, and everything that will be discussed with you will be treated confidential. You will also be assigned a false name or pseudonym, instead of using your real name to protect your identity. The information that you share will be voice recorded with your permission, to make data collection easier and 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 will only be 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 provided below, so that the researcher can contact you. Alternatively, the contact details of the researcher are available below, should you wish to contact the researcher directly.

Name: _____

Phone: _____

Email: _____

Yours sincerely,

Room 10-10, Humanities Building
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Lindie Bull
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Contact Number: 084 500 2256
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Appendix 5: Participant Letter of Informed Consent

UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Dept. of Social Work & Criminology

Humanities 100. Since 1919

19/06/2024

Researcher: Lindie Bull
Contact number: 084 500 2256
E-mail: lindie.bull@tuks.co.za
Supervisor: Charlene Carbonatto
Contact number: 012 420 2410
E-mail: charlene.carbonatto@up.ac.za

Dear Madam/Sir

LETTER OF INFORMED CONSENT

Section A: Research Information

Research Information

This letter invites you to participate in a research study on: *The psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng.* This letter provides a brief explanation of the purpose, procedures, risks, and benefits of the study. 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 in no way affect your access to services at Apricot Tree Centre. You are welcome to ask questions about the proposed study before signing the consent form.

Title of the study

Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng.

Purpose of the study

The purpose of the study is to explore the psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, South Africa.

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Email: Charlene.carbonatto@up.ac.za | www.up.ac.za

Procedures

You've been made aware of the study and have given the gatekeeper of Apricot Tree, Mrs. Abby-Jade Reason, your contact information, so the researcher can get in touch with you to 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 Benoni, Gauteng. A single interview will be held at a location that is convenient for you and the interview will take approximately 45-60 minutes. With your consent, the interview will be digitally recorded for accurate data collection purposes. The interviewing process will be guided by a semi-structured interview schedule. Your participation in this study will help the researcher to 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 will have the opportunity to ask any questions about the study and provide your informed consent before participating. If you so desire, you have the right to access your data at any time, which can be verified with you for accuracy after the transcription, as part of the process of checking the quality of the data. Results will be presented in a mini-dissertation format, which will be made available to the organisation and will be available in the University of Pretoria library. Your participation is greatly appreciated and will contribute to 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 their mental health, could be emotional for you as participant, therefore the researcher will provide debriefing after the interview to reflect on the interview experience. In the highly unlikely event of you experiencing emotional distress as a result of the interview, free counselling services will be made

available to you by a social worker, Lezanri Eksteen, who is available can be contacted at: 072 564 1597.

Benefits

Your participation in the study is voluntary. You will not receive any form of remuneration, compensation, or incentives for participating in the study. The study is about exploring the psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities. The findings of this study can inform social workers and other professionals of their interventions pertaining to rendering services to parents of children with intellectual

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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, without any 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 will only be used for research purposes. As the interview will be face-to-face, anonymity cannot be ensured. Your identity will be kept confidential and de-identified by using a pseudonym/false name when data is analysed and reported, in order to protect your identity. 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, or a conference paper and possibly in the future for further research purposes. The data collected will be kept confidential and will be 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:

Lindie Bull
0845002256
Lindie.bull@tuks.co.za

Please sign session B on the next page if you would like to consent to participate in this study.

Yours sincerely,

.....

Lindie Bull
Researcher

.....

Prof. CL Carbonatto
Supervisor

Room 10-10, Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 4202410
Email: Charlene.carbonatto@up.ac.za | www.up.ac.za

Section B: Informed consent of participant

I ……, (Full Name of participant) hereby declare that I have read and understood the above information. I was given adequate time to consider my participation in the study. I was also given the opportunity to ask questions and all of them were answered to my satisfaction. I hereby give consent to participate voluntarily in this study.

Participant: _____
Date: _____
Signature: _____

I……, (Full Name of the researcher) hereby declare that I have explained the information in Section A: Research Information to the participant and he/she indicated understanding the contents and was satisfied with the answers to the questions asked.

Researcher: _____
Date: _____
Signature: _____

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Appendix 6: Provision of free counselling services

Healing Minds

Healing begins here

5 April 2024

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

To whom it may concern,

I, Lezanri Eksteen, 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: Lezanri Eksteen
Organisation: Healing Minds Counselling
Qualification: Bachelor Of Arts Honours In Psychology
Contact details: WhatsApp - 072 564 1597
Registration Board: ASCHP
Registration Number: SWC/23/1701

Kind regards,
Lezanri Eksteen

SWC23/1701
eksteen4counselling.co.za
Online Counselling
072 564 1597

Appendix 7: Interview Schedule

Semi-structured Interview Schedule Research for MSW (Health Care)

Principal Investigator:

Biographic details:

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

Background:

1. Tell me about yourself and your family.
2. Tell me about your child's diagnosis, how and when you found out of their ID
3. Who is the primary caregiver of your child with ID?

Parenting experiences:

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

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 mental health skills you have gained from caring for your child with ID?

Resilience:

1. Tell me how caring for a child with ID has made you more resilient
2. What coping strategies do you use to manage mental health challenges?
3. Have you experienced burnout, and how did you overcome it?
4. 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. Anything else you would like to add?

Appendix 8: Change of Title Approval by the Deputy Dean and Chair, Postgraduate Committee, Faculty of Humanities

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: **23253674** Title: **Mrs**

Surname: **Bull** Initials: **L**

Course: **MSW (Healthcare)**

Department: **Social Work & Criminology**

Date of ethical clearance: **3 July 2024**

Ethics protocol number: **HUM 001/0524**

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

New research title (to be approved):
Psychosocial factors affecting the mental health of parents caring for children with intellectual disabilities in Benoni, Gauteng

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 CL Carbonatto
02391872

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)
N/A

ROUTE

1. SUPERVISOR:
Signature.....
Date 08/11/2024.....

2. DEPARTMENTAL RESEARCH/POSTGRADUATE COMMITTEE:
Signature .....
Date: **08/11/2024**

3. HEAD OF DEPARTMENT:
Signature.....
Date...11/11/2024.....

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...14 November 2024.....

5. STUDENT ADMINISTRATION:
Signature.....
Date..18 Nov 24.

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): To differentiate this student's study from the others on the 2023 group theme

ugust 2017 - Faculty of Humanities Postgraduate Committee and Ethics Committee