

**TOWARDS AN EXPLANATORY MODEL FOR CHALLENGING BEHAVIOUR IN
PERSONS WITH INTELLECTUAL DISABILITIES IN THE CAPRICORN DISTRICT,
LIMPOPO PROVINCE**

by

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THESIS

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DEDICATION

This study is dedicated to three groups of people:

a) The thesis is dedicated to my family, my husband Kgaogelo, my children Leago and Moagi. I am deeply indebted to the inspirations, patience, and sacrifices you made to enable me to complete this work.

b) The persons with intellectual disabilities, particularly those at Bana ba Thari and Benedict and Hope special school for children with intellectual disability. It was a great privileged to collect data in the two schools. I learned more about disability, I was warmed with your unique developmental challenges, and I was shown that there is more that humans can be grateful for. You have changed my perspective of life forever.

c) The teachers, parents and families of persons with intellectual disabilities. The frustrations, hardships and pain that you likely go through daily as you try to not only fight poverty and a lack of basic resources, but also continuously care and nurture your children with the intellectual disability, are unimaginable.

DECLARATION

I declare that **TOWARDS AN EXPLANATORY MODEL FOR CHALLENGING BEHAVIOUR IN PERSONS WITH INTELLECTUAL DISABILITIES IN THE CAPRICORN DISTRICT, LIMPOPO PROVINCE** thesis hereby submitted to the University of Limpopo, for the degree of Doctor of Philosophy in Psychology has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.



Lekota, PT

7 July 2020

Date

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ABSTRACT

Persons living with intellectual disabilities (ID) at times display behaviours that are a challenge for healthcare professionals, parents and teachers. These challenging behaviours are often presented in health-care, educational, or social care services by individuals with intellectual disabilities. However, what could be explained as challenging may be understood differently through cultures, beliefs or surroundings. The aim of the study was to conceptualise and develop an explanatory model for challenging behaviour in persons with intellectual disabilities. The study comprised twenty (23) participants who were parents and teachers of persons with intellectual disability. The target population of the study live in *Ga-Dikgale* and *Ga-Molepo* villages that are located in the Capricorn District, Limpopo Province. These villages were chosen because they have special schools for children with ID. A semi-structured, in-depth, one-on-one interview was used to collect data.

The data was analysed using thematic content analysis (TCA). Three superordinate themes emerged that covered the understanding of challenging behaviour from the participants. These themes were: (a) knowledge about challenging behaviour; (b) beliefs about causal explanations of challenging behaviour; and, (c) coping with challenging behaviour.

The results revealed that participants held varied beliefs regarding causal explanations of challenging behaviour. Cultural background of the participant seemed to play a critical role in shaping these beliefs. Additionally, three modes of coping were used by the participants in the study to cope with challenging behaviour. These are: cultural/traditional coping; religious coping; and, family and professional support methods. A Bio-Psycho-Socio-Cultural Model (BPS-C) was subsequently developed to explain challenging behaviour of persons with intellectual disability. This model integrates components of the Bio-Psycho-Social model (biological characteristics, behavioural factors, and social condition such as social support and family relationships) and cultural aspects to conceptualise challenging behaviour as understood and explained by parents and teachers of persons with intellectual disability.

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Abbreviations and acronyms used

APA – American Psychiatric Association

BPS – Bio-psychosocial

DSM-5 – Diagnostic and Statistical Manual for Mental Disorders (5th addition)

HBM – Health Belief Model

ID – Intellectual Disability

NGOs – Non-governmental Organizations

PWD – People with Disabilities

PWID – People with Intellectual Disability

PWSID - People with severe Intellectual Disability

SA – South Africa

SID – Severe Intellectually Disability

Stats SA – Statistics South Africa

WHO – World Health Organization

ZCC – Zion Christian Church

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CHAPTER 1

INTRODUCTION AND BACKGROUND

1.1 INTRODUCTION

The purpose of this study was towards developing an explanatory model for challenging behaviour in persons with intellectual disabilities by their parents and teachers. One of the main objectives of the study was to understand and describe the notions of challenging behaviours in persons with intellectual disabilities by parents and teachers, including what they believe to be the cause of challenging behaviours. Additionally, the study sought to determine their beliefs about appropriate interventions to utilise for coping with these challenging behaviours. Finally, the study aimed to conceptualise and develop a culturally informed explanatory model to explain challenging behaviour in persons with intellectual disabilities.

1.2 Background to the study

Persons living with intellectual disabilities at times display behaviours that are a challenge for healthcare professionals, parents and teachers (Hinshaw & Arnold, 2015). For behaviour to be considered as challenging, it should be understood to be having characteristics such as being unsafe, terrifying, stressful or irritating (Ali, Blickwedel & Hassiotis, 2014). However, what could be explained as challenging may be understood differently through cultures, beliefs or surroundings (Nastasi, et al., 2015). According to Hutchinson, et al. (2014), challenging behaviour is usually described as pervasive maladaptive behaviours. They further indicate that such behaviour usually display significant opposing outcomes on the quality of life or well-being and protection of the individuals and/or those around them. Challenging behaviour commonly include inappropriate sexual behaviours, bodily aggression to objects or people, self-injury, and offending attitudes (such as arson, kicking, bullying, punching or stealing), rituals and/or mannerism (Davies & Oliver, 2016).

Concerns of challenging behaviour would usually comprise substantial impairment of the health or quality of life of the individuals living with intellectual disabilities, or the lives of those who care for them or educate them (Klaver et al., 2016). In most countries, parents

are usually the primary and main foundation of influence behind the development of character and the progress of an individual (Hayes & Watson, 2013). In most cases, parents are ordinarily supporters of persons with intellectual disabilities' development through education because challenging behaviour is likely to commence in childhood and may aggravate overtime (Marsh & Ng, 2017). In the case of teachers, their role is to support and take better care of persons with intellectual disabilities at school. They may also need support to be able to interpret persons' with intellectual disability's behaviour (Jacobs, et al., 2016).

1.3 Research problem

Challenging behaviour is often displayed by individuals with intellectual disabilities in health-care, educational, or social care services (Hutchinson, et al., 2014). This behaviour in general, commonly involves a display of violence, harmfulness, self-injurious behaviour, irritability tantrums, over-activity, crying/yelling, scattering objects around, wandering, night-time disturbance, unbearable personal habits, inconsiderate behaviour, sexual misbehaviour, and attention-seeking behaviour, among others (Shawler & Sullivan, 2017).

Several models have been developed to explain challenging behaviour. These, among others, include the attribution model (Clarke, Taylor, Lancaster & Remington, 2015), psychodynamic model (Clarke, et al., 2015) and the biopsychosocial model (Machalicek, et al., 2014). For example, the cognitive behavioural model (Clarke, et al., 2015), posits that people's behaviour is influenced by what they think, visualise or imagine. A closer look at models to explain challenging behaviour suggests that most of these tend to focus on psychic and behavioural experiences while not paying attention to socio-cultural factors (Shenoy, 2016). This suggests that these models may be incomplete, and thus not necessarily applicable in every setting. According to Nastasi, et al. (2015) there is a need to develop explanatory models of behaviour that are informed by the cultural reality of the people affected. In view of this limitation in most explanatory models of challenging behaviour, there is a need to develop culturally informed explanatory models to augment existing models of challenging behaviours. The present study hopes to fill this gap by exploring parents' and teachers' notions of challenging behaviour in persons with intellectual disabilities with a view to develop a culturally relevant explanatory model.

1.4. Significance of the study

The present study could potentially achieve the following:

- The explanatory model developed through this study can assist in the improvement of treatment and care for persons with intellectual disabilities.
- Understanding parents' and teachers' notions and experiences of challenging behaviour will advantage researchers, policy makers, other non-governmental organisations, and others to understand intellectual disability from the context of the family so as to assist them to provide appropriate interventions.
- This study would help psychologists with the relevant explanatory models that are culturally informed to avoid biased assessments and treatment interventions.

1.5 Purpose of the Study

1.5.1 Aim of the study

The aim of the study was to conceptualise and develop an explanatory model for challenging behaviour in persons with intellectual disabilities.

1.5.2 Objectives of the study

- To understand and describe the notions of challenging behaviours in persons with intellectual disabilities by parents and teachers;
- To determine the causal explanations of challenging behaviours in persons with intellectual disabilities by parents and teachers;
- To establish parents' and teachers' beliefs about appropriate interventions for challenging behaviours in persons with intellectual disability;
- Based on the parents and teachers' notions, causal explanations and beliefs about appropriate interventions, develop and articulate an explanatory model on challenging behaviour in persons with intellectual disabilities.

1.6 Operational definitions of concepts

- **Explanatory model:** An explanatory model is a valuable narrative and clarification of why and how a thing works or an explanation of why a phenomenon is the way it is (Craver, 2014). An explanatory model in the context of the present study will be

understood to mean an explanation of challenging behaviour in persons with intellectual disabilities as understood by parents, teachers and policy makers.

- **Challenging behaviour:** This is defined as problematic behaviour or socially unacceptable behaviour that challenges culturally or common ways of living. It could also be defined as behaviour that hinders normal functioning of an individual, and likely to result in limited or denied access to ordinary use of community facilities (Emerson, 2001). In the present study, challenging behaviour will be understood to refer to behaviour characterised by a person portraying abnormal, aberrant, disordered, disturbed, dysfunctional, maladaptive and problem behaviours.
- **Intellectual disability:** According to Schalock, Verdugo and Gomez (2011) intellectual disability refers to limits in intellectual functioning and life skills such as communicating, taking care of oneself, and independent living. The limits can impact the persons with intellectual disabilities to develop slowly to some practical, conceptual and social skills than a typical child. For the purpose of the present study, intellectual disability will mean limitations in intellectual functioning and lack adaptive behaviours or life skills necessary for day-to day functioning, such as being able to interact with others, communicate effectively and take care of oneself.

1.7 Outline of the thesis

The thesis is organized in eight chapters. **Chapter 1** is comprised of the introduction, background to the study, the research problem, purpose and objectives of the study, and the significance of the study. **Chapter 2** comprises literature review, and begins with a presentation on the notions of challenging behaviour. The parents and caregivers experiences of living with persons with intellectual disability are also outlined in this chapter, together with the categories of intellectual disabilities. The last section of this chapter presents the teachers experiences of persons with intellectual disability. **Chapter 3** is the presentation of the theoretical framework underpinning the study. The Biopsychosocial model and the Afrocentric paradigm, the two theoretical frameworks adopted in the study, are outlined in this chapter. **Chapter 4** comprises a presentation of the methodology followed in conducting the study. The research design, data collection

and analysis methods are outlined in this chapter. Issues of quality as they pertain to this study are outlined, followed by a presentation of ethical issues.

Chapter 5 is a presentation of the findings of the study. The findings are presented as themes revealed in the participants' notions of living with persons with ID who display challenging behaviours. This chapter is divided into three parts. Part A comprises of the presentation of the demographic profile of the participants as well as the summaries of the interviews. Part B comprises three themes that emerged from the study and Part C is made up of psychological interpretation of the shared experiences of the participants.

Chapter 6 is a presentation of an explanatory model that this study sought to develop.

Chapter 7 is a discussion of the findings in relation to the literature. The discussion of the proposed model to explain challenging behaviour in the context of this study is also presented in this chapter. The last chapter, **Chapter 8**, provides a summary of the findings, including conclusions, and recommendations of the study. The limitations of the study are also outlined in this chapter. Finally, the implications of the study in terms of theory, practice, training, policy, and future research are highlighted in this chapter.

CHAPTER 2

LITERATURE REVIEW

In the first part of this chapter, intellectual disability and the four degrees that designate the severity of impairment is presented. In the second part of the chapter, the notions of challenging behaviours are discussed whilst the third part focuses on parents and caregivers' experience of living with persons with intellectual disability. In the fourth part of the chapter, a presentation is given of teachers' experiences of working with persons with intellectual disability. This is followed by a discussion on the challenges of working with intellectually disabled children. The sixth part outlines coping strategies that are commonly used whilst the last part of the chapter focuses on the role of culture and spirituality in challenging behaviour.

2.1 Prevalence of Intellectual Disability in South Africa

Intellectual Disability prevalence in South Africa surpasses most high-income countries (Maulik et al. 2011; McKenzie 2016; Tomlinson et al. 2014). In this sense, foetal alcohol spectrum disorder (FASD) could be an easily preventable cause of ID, however South Africa's prevalence rate of 6% – 9% is one of the world's highest (Adnams 2010; De Vries et al. 2013; Roozen et al. 2016; Urban et al. 2008).

South African data accuracy on ID prevalence among children between 2–9-year-old were collected in the 1990s (Kromberg et al. 1997, 2008; Christianson et al. 2002). ID was not directly measured during the 2011 national census, thus the statistics on children with disabilities aged 0–4 years were not profiled (Statistics South Africa [SSA] 2014). Accurate South African ID data is rare (Du Plessis 2013). During the last consensus, it was discovered that 3.2% of people aged 5 years and older have mild and 1% of people have severe difficulties 'in remembering or concentrating' (SSA 2014:34)

Despite the approval of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (The United Nations [UN] 2006) a decade ago, South Africa's dualist legal system has yet to incorporate the international conventions into domestic legislation on behalf of PWID (Huus et al. 2015). The lawmakers' lack of understanding of what 'intellectual disabilities actually *mean*' was officially gazetted in parliament

(Department of Social Development [DSD] 2015). Furthermore, although the White Paper on the Rights of Persons with Disabilities (DSD 2015) commits to PWID, only a little is mentioned of how these commitments will be implemented or monitored (De Vries et al. 2013; Drew et al. 2011; Kopel 2017; Roy et al. 2012).

The lack of educational programmes for children with intellectual disability (CWID), results in parents in countries like South Africa easily becoming unpaid caregivers because care burdens and lack of support obstruct their pursuit of employment (Mckenzie & McConkey 2016). Absence from school also limits exposure of CWID to formal teaching on sexual health programmes (Rohleder & Swartz 2009). This is problematic, because more than two-thirds of adolescents with ID are likely to face risk of sexual abuse before the age 18, while up to 83% of women and 32% of men with ID are more likely to face risk of being sexually assaulted in their lifetime (Byrne 2017; Peckham 2007).

Frequent violation of rights of PWID in South Africa relate to physical abuse, exclusion, barriers to accessing medical and mental health services, occupational restrictions, denial of marriage or parenting, involuntary confinement, financial exploitation, unemployment, and living safely outside of institutions (Drew et al. 2011; Erasmus, Bornman & Dada 2016). These rights are violated in public, places of education and work, family homes, care centres, health care settings, courts, civic offices and police stations, (Drew et al. 2011).

Yet, we know less about South African evidence-based studies on which to shape better ID privileges practice. A high number of ID research results from high-revenue countries where PWID enjoy various government and community supports but is not always relevant to settings in which most PWID live (Glicksman et al. 2017; Groce et al. 2011a, 2011b; McKenzie, McConkey & Adnams 2013a; Robertson et al. 2012). In this regard, we aim to explore significant South African ID rights issues, clarify key concepts, provide a synopsis of existing evidence and synthesise quantitative and qualitative studies (Arksey & O'Malley 2005; Daudt, Van Mossel & Scott 2013; Harden 2010; Peters et al. 2015).

2.2 Intellectual disability

The degree of impairment from an intellectual disability varies widely. The types of cognitive impairment were divided by experts into four categories: mild intellectual disability, moderate intellectual disability, severe intellectual disability, and profound intellectual disability. DSM-V places less emphasis on the degree of impairment (i.e. IQ scores) and more on the amount and type of intervention needed (APA, 2013). The person's ability or impairment across these three skill areas: conceptual, social, and practical life skill are measured and considered by mental health professionals. IQ scores are important in assessing the level of intellectual disability, corresponding IQ range is assigned for each level discussed below.

2.2.1 Mild intellectual disability

The majority of people with ID are classified as having mild intellectual disabilities. They have an IQ range of 50 to 69 (APA, 2013). About 85 percent of people with intellectual disabilities fall into the mild category and many even achieve academic success. A person who can read, but has difficulty comprehending what he or she reads represents one example of someone with mild intellectual disability.

Individuals with mild ID are slower in all areas of conceptual development and social and daily living skills. These individuals can learn practical life skills, which allow them to function in ordinary life with minimal levels of support (Burke et al., 2012). Some of the symptoms of mild intellectual disability include taking longer to learn to talk, but communicating well once they know how. They also become fully independent in self-care when they get older. They are also likely to have problems with reading and writing, social immaturity and they benefit from specialized education plans.

2.2.2 Moderate intellectual disability

Individuals with moderate ID can take care of themselves, travel to familiar places in their community, and learn basic skills related to safety and health. They generally have an IQ range of 35 to 49. People with moderate intellectual disability have fair communication skills, but cannot typically communicate on complex levels. They may have difficulty in social situations and problems with social cues and judgment. Individuals with moderate

ID may be slow in understanding and using language and may have some difficulties with communication. They can learn basic reading, writing, and counting skills but generally unable to live alone even though they can often get around on their own to familiar places (Burke et al., 2012). They can take part in various types of social activities through training. These people can care for themselves, but might need more instruction and support than the typical person because their self-care requires moderate support (Sadock & Sadock, 2015). About 10 percent of those with intellectual disabilities fall into the moderate category.

2.2.3. Severe intellectual disability

Severe ID manifests as major delays in development, and individuals often have the ability to understand speech but otherwise have limited communication skills (Sattler, 2002). They generally have an IQ range of 20 to 34. Despite being able to learn simple daily routines and to engage in simple self-care, individuals with severe ID need supervision in social settings and often need family care to live in a supervised setting such as a group home. People with severe intellectual disability have strong relationships with key people in their lives because they usually recognise familiar people. They mostly rely on facial expressions, gestures and body language to express their needs or feelings because most of them have little or no speech and those supporting them must be alert at all times in interpreting changes in their behaviour (Sadock & Sadock, 2015).

The symptoms of severe ID usually include noticeable motor impairment, severe damage to, or abnormal development of, their central nervous system.

2.2.4. Profound intellectual disability

Persons with profound intellectual disability often have congenital syndromes (Sattler, 2002). Profound intellectual disability represents an IQ of less than 20 (APA, 2013). These individuals cannot live independently, and they require close supervision and help with self-care activities. They have very limited ability to communicate and often have physical limitations. Individuals with mild to moderate disability are less likely to have associated medical conditions than those with severe or profound ID. The symptoms of profound ID include inability to understand or comply with requests or instructions possible immobility incontinence very basic nonverbal communication, inability to care for

their own needs independently and the need of constant help and supervision (Sadock & Sadock, 2015).

2.3 Notions of challenging behaviour

Challenging behaviour has often been associated with mental illness (Sheehan, et al., 2015; Deb, Thomas, & Bright, 2020). For example, Thakker, Bamidele, Ali and Hassiotis, (2012) suggested that several studies have highlighted common aetiological factors that are responsible for challenging behaviour and psychiatric disorders in people with intellectual disabilities, and although there is an overlap in the symptoms, they are thought to be different phenomena. Challenging behaviour often have serious consequences for the affected individuals and their families as they (challenging behaviour) are perceived as embarrassing and humiliating (WHO, 2001). Hostile social reactions to people with intellectual disabilities may be due to misconceptions about the nature, causes, consequences and management of these conditions. Misconceptions often include association of challenging behaviour with dangerousness, spirit possession, infectiousness, violence and incompetence. Supernatural attributions, such as spirit possession, and behavioural symptoms also tend to be associated with challenging behaviour, more especially in African context (Idemudia, 2015).

Cultural conceptualisation of intellectual disability have been found to vary across diverse racial and ethnic groups, given the diverse cultural norms, resources and support available to the parents (Qayyum, Lasi & Rafique, 2013). Researchers have found that there are often diverse conceptions of mental illness in sub-Saharan Africa. For example, in an ethnographic study of the health care system in Zimbabwe, Patel (1998) reports diverse conceptions of mental illness among village health workers, traditional medical practitioners, community psychiatric nurses and relatives of people with mental illnesses. Community psychiatric nurses conceptualise mental illnesses in biomedical terms, such as depression and psychosis, while other care providers, (for example, families) conceptualised mental illness in cultural terms by referring to it as *kupenga* (madness). Patel (1998) equates *kupenga* (madness) with the biomedical concept of acute psychosis. Psychosis is frequently reported as exemplifying mental illness in Low and Middle Income Countries (LAMICs) (Patel, 1998). Patel (1998) also reports, in the Zimbabwean study

mentioned above, that after probing, primary care providers identified other forms of illnesses of the “mind” or “soul”, such as *kufungisisa*, *mahepo* (bad airs often associated with witchcraft) and *pfukwa* or *ngozi* (angry alien spirits of persons who were murdered). Such probing was possible because the researcher adopted a flexible and culturally appropriate research methodology.

A study by Petty, Bacarese-Hamilton, Davies and Oliver, (2014) found that challenging behaviours consisted of repetitive, overactive and impulsive behaviours from a younger age. Validating the significance of impulsivity and overactivity, other studies by Hinshaw and Arnold (2015) identified relationships between aggressive behaviour with attention deficit hyperactivity disorder and self-injurious behaviours. For example, the study by Davies and Oliver (2016) found that aggression was associated with self-injury, destructive, repetitive, restricted, overactive and impulsive behaviours. The studies by both Finlayson et al. (2015) and Davies and Oliver (2016) mentioned that there is a possibility that the behavioural signs of repetitive behaviour and overactivity\impulsivity influence the prediction of the future progress of self-harmful and violent behaviour displayed by children with the current signs of ID.

Different child variables with higher levels of parental stress, as well as the occurrence of mental illness in the child (e.g., Berg-Nielsen, Vikan, & Dahl, 2002; Brannan & Heflinger, 2001), causes of ID (e.g., Blacher & McIntyre, 2006), the severity of ID (e.g., Holden & Gitlesen, 2004), behavioural problems (e.g., McStay et al., 2014), adaptive abilities (e.g., Haveman et al., 1997), social skills (T. B. Smith et al, 2001), SEP and hardship (e.g., Hatton & Emerson, 2009), and family characteristics (e.g., Frey, Greenberg, & Fewell, 1989) has been linked with research. Terms such as behavioural difficulties and problem behaviours are used to refer to challenging behaviour (CB). CB refers to an umbrella term that exemplifies several forms of various behaviours (Deb, Thomas, & Bright, 2001). Behavioural difficulties and problem behaviours are terms used in the present study to refer to the different behaviours that reside under the category of challenging behaviour.

2.3.1 The phenomenon of CB in services for people who have ID

Challenging behaviour among persons who have ID has received extensive attention in research (McClintock, Hall, & Oliver, 2003). A generally accepted definition of problem

behaviour considers risk to the self or others as preventing optimal access to community resources (Kushlick, Trower, & Dagnan, 1997). Challenging behaviour definition by Emerson is widely used in the field of ID research. He defined challenging behaviour as: behaviour which is likely to seriously limit or delay access to and use of ordinary community resources or behaviour of such an frequency, intensity, and duration that the physical wellbeing of the person or others is likely to be placed in danger (Emerson, 1995).

Different forms of the classification of CB remains an argumentative issue in research for a number of reasons: First, different criteria of discrete sets of behaviours have been employed across different studies and research has often been inconsistent in its classification of challenging behaviours (Cooper et al., 2009; McGillivray & McCabe, 2006). Second, investigated studies of CB have included children and adults in the same sample. The findings from these studies were not sensitive to the role of developmental considerations across different age-groups (Myrbakk & Von Tetzchner, 2008). Third, the use of different methodological designs made it difficult to replicate findings, particularly when different data collection methods were used (Deb et al., 2001; Dilworth, Phillips, & Rose, 2011). Fourth, earlier ID research has also been criticised for its lack of standardised criteria to define and operationalize different forms of problem behaviours (Joyce, Ditchfield, & Harris, 2001). For example, some studies managed to only focus on severe self-injurious behaviour while others included milder forms of self-injury (Joyce et al., 2001).

The lack of standardised criteria and operationalised descriptions of challenging behaviours have made it difficult to establish its prevalence rate. The prevalence of CB has accordingly been estimated to range between 4% and 64% of persons who have ID (Deb et al., 2001). However, it is generally considered that challenging behaviours are prevalent among 10-20% of individuals who have ID (De Winter et al., 2011; McClintock et al., 2003; Totsika et al., 2011). In order to address the lack of consistency about standard criteria and the operationalisation of different forms of challenging behaviours, the DSM 5 has published a hierarchical diagnostic system, the Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Intellectual Disabilities.

The DSM 5 is based on expert opinion and provides diagnostic criteria for psychiatric disorder among adults who have ID. The DSM 5 also describes different forms of problem behaviours such as; verbally aggressive behaviour, physically aggressive behaviour, destructive behaviour, self-injurious behaviour, sexually-inappropriate behaviour, oppositional behaviour, demanding behaviour, wandering behaviour and other problem behaviours such as non-epileptic seizures; psychogenic polydipsia, spitting, playing with food; deliberate urinary and faecal incontinence; soiling and or smearing; throwing objects; hoarding; stealing; begging; making hoax telephone calls; repeated lying; etc.

In order to assess whether the abovementioned challenging behaviours require further clinical attention, Kaplan and Sadock (2011) has adopted diagnostic criteria to assess the frequency, severity and duration of different challenging behaviours:

2.3.1.1. General diagnostic criteria for challenging behaviours

A) The challenging behaviour is of significant frequency, severity or chronicity as to require clinical assessment and special interventions/support.

B) The challenging behaviour must not be a direct consequence of other psychiatric disorders (e.g., pervasive developmental disorders, non-affective psychotic disorder, depressive episode, generalised anxiety disorders, obsessive-compulsive disorder, and personality disorders), drugs or physical disorders (Lee & Kiemle, 2014).

C) One of the following must be present:

1. The challenging behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his or her lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning. (Cooper et al., 2009)

2. The challenging behaviour presents significant risks to the health and/or safety of the person and/or others.

D) The challenging behaviour is persistent and pervasive. It is present across a range of personal and social situations, although may be more severe in certain identified settings.

The diagnostic criteria of challenging behaviours describe their negative impact on adults who have ID and their families. Challenging behaviours are often associated with unsuccessful adjustment in community-based accommodation settings and family living (Joyce et al., 2001). There is also evidence of associations between burden of care, caregiver strain and the challenging behaviours of service users in services for persons who have ID (Mills & Rose, 2011). The person who displays challenging behaviours might also be subjected to drastic intervention strategies (Allen & Lowe, 1995).

These diagnoses are ordered in multiple axes that are hierarchically constructed, i.e., clinical diagnoses on an axis should only be considered once it has been established that the symptoms are not better accounted for by the previous axis. The hierarchical approach is taken directly from the DSM 5 and provided below (Brown & Barlow, 2005):

Axis I: Level of learning disabilities

Axis II: Causes of learning disabilities

Axis III: Psychiatric disorders

Level A: Developmental disorders

Level B: Psychiatric illnesses

Level C: Personality disorders

Level D: Problem behaviours

Level E: Other disorders (p.13).

It is estimated that the prevalence of psychological disorder among people who have ID is 2 - 3 times higher than the general population (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008; Holden & Gitlesen, 2004; Kwok & Cheung, 2007). The hierarchical diagnostic system provides clarity about the structure that clinicians should use when conceptualising complex clinical conditions that include challenging behaviour. If problem behaviour is accounted for by developmental disorder, a psychiatric condition or personality disorder, specifiers should be added that describe the form of challenging

behaviour according to the categories or forms of challenging behaviours (American Psychiatric Association, 2013).

2.3.1.2. Challenging behaviour/s due to pervasive developmental disorder (type/s)

A. The challenging behaviour is of significant frequency or severity to require special interventions/support in addition to those for the pervasive developmental disorder.

B. The challenging behaviour/s is/are a direct consequence of pervasive developmental disorder (Coetzee, 2016).

C. One of the following must be present:

1. The challenging behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning.

2. The challenging behaviour presents significant risks to the health and/or safety of the person and/or others.

D. The challenging behaviour is persistent and pervasive. It is present across a range of personal and social situations, although it may be more severe in certain identified settings.

2.3.3.3. Challenging behaviour/s due to psychiatric disorder

A. The challenging behaviour is of significant frequency or severity to require special interventions/support in addition to those for the psychiatric illness. (Cooper et al., 2009)

B. The challenging behaviour/s is/are a direct consequence of psychiatric illness.

C. One of the following must be present:

1. The challenging behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his or her lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning.

2. The challenging behaviour presents significant risks to the health and/or safety of the person and/or others.

D. The challenging behaviour occurs during the psychiatric illness. It is present across a range of personal and social situations, although it may be more severe in certain settings

Aggressive behaviour among adults who have ID

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria for aggression are provided below:

IIID 1.2 Verbally aggressive behaviour

A. General diagnostic criteria for problem behaviour are met.

B. Verbal aggression must have occurred on at least three occasions in the preceding six-month period, for example the person uses his or her voice in a violent or threatening manner. This may be impulsive or planned, and must occur in the context of minimal or no provocation by others.

IIID 1.3 Physically aggressive behaviour

A. General diagnostic criteria for problem behaviour are met.

B. Physical aggression must have occurred on at least three occasions in the preceding six-month period, for example the person uses or threatens physical violence. This may be impulsive or planned, and occurs in the context of minimal or no provocation by others. Severity may range from pushing, slapping, and physically intimidating, to punching, kicking, biting, pulling the hair of others and more serious physical assault.

IIID 1.4 Destructive behaviour

A. General diagnostic criteria for challenging behaviour are met.

B. Destructive behaviour must have occurred on at least three occasions in the preceding six-month period, for example the person damages property, such as tearing paper and fabrics, smashing furniture and glass, to more serious property damage and fire setting.

This may be impulsive or planned, and occurs in the context of minimal or no provocation by others.

Aggressive behaviour remains one of the most difficult forms of behavioural problems for families and ID services to manage (McDonnell, 2010). As such, aggression is among the most frequent forms of challenging behaviour that is reported in community and residential ID services (Cooper et al., 2009; Felce et al., 2015; Lowe et al., 2007; McDonnell, 2010). Studies have highlighted the negative impact of aggression on a person's self-esteem, social relationships and overall quality of life (e.g., Lowe et al., 2007). It is also associated with a breakdown of community residential placement and employment (e.g., Cooper et al., 2009; Felce et al., 2015; Lowe et al., 2007); and aggression adversely affects families, including mothers and siblings (McIntyre et al., 2002). Aggression has also been directly implicated in forms of offending behaviour and personality disorder (e.g., Alexander et al., 2010; Lindsay et al., 2006; Tyrer, Oliver, & Tarabi, 2014). Prevalence studies of aggression in the ID population have yielded highly varying results of between 2.1% to 51.7% (Cooper et al., 2009; Felce et al., 2015). Similar to the wide range of prevalence rates that have been reported in studies that have focused on challenging behaviours, the varying prevalence rates of aggressive behaviour could be attributed to different methodological designs (Cooper et al., 2009).

Cooper and her colleagues (2009) have conducted a large longitudinal study that was based on a rigorous methodological design: all the adults who have ID within the Greater Glasgow Health Board area were asked to partake in the study and 65.5% agreed to participate. From a cohort of 1 023 adults, 651 persons took part in the study, and 100 participants met the DSM5 criteria for aggression. The study had considerable strengths that included a high rate of retention between the two intervals of measurement, the use of a defined population area to recruit participants, and the use of DSM 5 criteria to measure aggression. However, the authors stated that a cohort of just over a thousand participants was not large enough to comprehensively explore the incidence of aggression and isolation of aetiological patterns (Cooper et al., 2009).

Research has found that challenging behaviours such as aggression, destructive behaviours, sexually-inappropriate behaviours, oppositional behaviours, demanding

behaviours and wandering behaviours are more prevalent among younger persons between 20 and 35 than older adults (Tyrer et al., 2006). Aggression and self-injurious behaviours also shows an inverse relationship with severity of ID, i.e., the prevalence of oppositional behaviours is higher among people who have severe and profound ID (Crocker et al., 2006). While most of the earlier studies have found that men more frequently engage in aggressive behaviour and wondering behaviour, the abovementioned study by Cooper and her colleagues (2009) has identified a higher prevalence rate of aggression among women.

Aggression has also been described as expressions of behavioural phenotypes, e.g., fetal-alcohol spectrum disorder. Pervasive developmental disorder and ADHD have consistently been linked with increased aggression but the relationship between aggression and psychopathology remains inconclusive although (Cooper et al., 2009).

2.4. Parents and caregivers' experiences of living with persons with intellectual disabilities

Several studies have suggested that parents of persons with intellectual disabilities often experience more stress than those of normal persons (Hayes & Watson, 2013; Woodman, Mawdsley, & Hauser-Cram, 2015). Such stresses were found to relate empirically to the higher levels of behavioural problems frequently exposed by children with disabilities than to children's levels of intellectual or developmental skills (Mitchell, Szczerepa & Hauser-Cram, 2016). To bear a child with intellectual disability is a traumatic and devastating experience for parents. For example, Scior and Furnham (2016) point out that a parent's initial reaction to a child with intellectual disability is likely to be negative and similar to those related to bereavement. This is followed by a period of questioning which may go on for many years as to why this should have happened to them. They may blame themselves or each other as to why they have given birth to an intellectually disabled child (Findler, Jacoby & Gabis, 2016). Parents may also develop feelings of anger, depression, denial, guilt, and stressors.

It is family members, in particular mothers, who provide the most support to their children with an intellectual disability, leaving them more likely to experience stress (McConkey et

al., 2006). This may in turn affect the health of both child and parent and may impact upon family relationships. Hassall et al. (2005) suggest that the parents of a child with an intellectual disability are significantly more likely to experience parenting stress than parents of children who do not. Furthermore, their levels of stress are affected by levels of formal support from professionals and social support from partners, teachers, family members and friends (Hassall et al., 2005). Research by McConkey et al. (2004) has shown that services do not always address the needs of parents and do not offer continual support; some families felt that services did not always fit their individual needs. The most effective approaches to meet the needs of children with intellectual disabilities and their families is described by King et al. (2003) as one that is family centred in nature and one that adapts to fit with the needs of both the child and his or her family.

A study by Genik, Pomerleau, McMurtry and Breau (2017) has proposed several influences that may result in parents being compassionate and helpful for children with intellectual disabilities. These include the family's cultural values and beliefs, financial resources and the capacity to provide treatment for children with intellectual disabilities (Qayyum, et al., 2013).

2.5. Teachers' experiences of persons with intellectual disabilities

A number of studies (each using different methodological approaches) have investigated teachers' notions of challenging behaviour in persons with intellectual disabilities (Crone, Hawken, & Horner, 2015; Genik, Pomerleau, McMurtry, & Breau, 2017; Poppes, Van der Putten, Ten Brug, & Vlaskamp, 2016; Shenoy, 2016). For example, in a study involving nineteen (19) staff members who have worked in residential units for people with intellectual disabilities and challenging behaviours in London, staff members were asked to explain their notions challenging behaviour (Poppes, Van der Putten, Ten Brug, & Vlaskamp, 2016). More than fifty percent of these staff members defined challenging behaviours as behaviours that were difficult for them work with. Some of these staff members further explained these to be behaviours that are difficult to understand and deal with, and that these behaviours were either unusual or intolerable. Fascinatingly, 26% of the interview sample specified that challenging behaviours are activities or actions that needed to be controlled or changed. During the interviews, they were

asked about the kinds of behaviours they considered to be "challenging". The participants mentioned aggression, self-injury, destructive behaviours, and additional "inappropriate" actions (undressing, yelling, repetitive behaviours, sexual behaviours).

A few other studies have indicated that at times, some teachers of individuals with intellectual disability get discouraged and frustrated with their employment or became angry toward their occupation and also experience burnout (Stoesz, et al., 2016 & Hutchinson, et al., 2014). These incidents of burnout often happen when these teachers experience physical and emotional exhaustion as a result of prolonged stress or frustration (Brunsting, et al., 2014). These outcomes associated with these burnout of teachers can cause teacher health issues, teacher attribution, negative student outcomes and also for students to show more challenging behaviours in their classrooms (Brunsting, et al., 2014).

Experiences of working with intellectually disabled learners may be positive or negative based on a number of factors. Nalbant, Baran, Samut, Aktop and Hutzler (2013) investigated attitudes towards teaching students with intellectual disability within a representative sample of secondary school physical education teachers. The study sought to determine the effects of age, gender, teaching experience, and having acquaintance with intellectual disability (ID) and students with ID on their attitudes. The study findings revealed that physical education teachers had mixed attitudes towards including students with ID in their classes. Physical education teachers who were young, had acquaintance with ID and less teaching experience had more favourable attitude scores than the others.

In Turkey, it appears that the introduction of compulsory adapted physical activity classes in the physical education teaching training curriculum since 2000 resulted in young teachers having more favourable attitude scores. The differences between the younger and older teachers, as well as below and above 10 years in service was suspected to be related to the change of physical education teaching curriculum in 2000. The lack of the effect of having a student with intellectual disability in the class indicated that the teachers participating in the study did not perceive enough positive experiences. It has been

suggested that in order to improve attitudes, teachers need to experience self-efficacy in being able to adapt their teaching for inclusion (Nalbant et al., 2013).

Another study by Kaur and Arora (2010) sought to find out the experiences of families of intellectually disabled children. The findings supported the fact that children suffering from mental handicap are considered as a burden by their family members. Furthermore, it was found that negative parental attitudes lead to rejecting attitudes towards intellectually disabled children which adversely affect the interaction within the family and also with outsiders. Often the family members become worn out and get discouraged while dealing with their mentally handicapped child. Hence, the presence of an intellectually disabled child shakes the foundation of the whole family.

Families of individuals with intellectual disability often experience stress in relation to caring for their family member. Previous research has determined that parents of children with ID experience greater stress compared to parents of children without disabilities (Syeda, Weiss & Lunskey, 2011). Stressors include the added caregiving demands required to manage problem behaviours, and the lack of financial resources, when the focus is on caregiving rather than working. Stressors associated with taking care of a family member with ID can have a significant negative impact on families, and in some cases, lead to crisis. Most families referred to the specialised mental health service for adults with ID were close to being or were in crisis. This distress is associated with low levels of empowerment and hardiness, and high levels of compassion fatigue. Many families reported difficulties with their finances, inability to work, and that caregiving responsibilities made it difficult to function day to day (Syeda, Weiss & Lunskey, 2011).

Due to the amount of contact that teachers have with intellectually disabled children, their attitude can impact significantly on these children. A study conducted by Govender (2002) revealed that special class teachers expressed more favorable attitudes to the mentally retarded than do teachers of ordinary children (Rawlins, 1983). According to Rawlins (1983), only a small minority of teachers were in favour of integrating the mentally retarded into regular classes. He offered an explanation that regular education teachers do not possess special positive attitudes towards children labelled as mentally retarded.

The move towards integration should be accompanied by programmes designed to influence and change teachers' attitudes to a more positive one (Nalbant et al., 2013).

A study conducted by Stephen and Braun cited in Rawlins (1983), showed that teachers who had taken courses in special education were more willing to accept handicapped children into their classrooms than were those who had not taken such courses. In a cross-cultural study of attitudes towards the mentally retarded in South Africa, Rawlins (1983) found out that isiZulu speaking teachers and Zulu University students strongly rejected the mentally retarded. However, the study also revealed that Zulu high school pupils were more accepting of this disability. In his study of the perception of black university students of the handicapped person in an isiZulu speaking community, he further found out that student' attitudes were favourable towards the handicapped. However, the author reports incongruence between students' beliefs and behaviours. The study has revealed a tendency of the students to avoid contact with handicapped people. Rawlins (1983) attributes this rejection of intellectual disability to the elevated status and authority given to individuals with advanced education, more especially in the isiZulu culture.

According to Human Rights Watch (2015), blacks in South Africa perceive higher education as a means to improve both their political and social lives and thus would reject anything that represents the opposite. Johnson (1950) in Rawlins (1983) found out that mentally retarded children were the most rejected children in twenty regular classes. Johnson concludes that these children were rejected because of their behaviour in the classrooms, playground and outside the school environment. Rawlins (1983) also cites a study by Lapp (1957) with contrary findings. He found out that mentally retarded children were more rejected among their peers in special classes than among their peers in regular classes. Willner and Smith (2008) observed that mentally retarded children in regular classes have a lower social status and are less well accepted by other children. Philpott and McLaren (2011) looked into the acceptance of the retarded by their non-retarded peers. He suggests that retarded children are very seldom chosen as a best friend, irrespective of the organisational context of special classes or integrated settings.

2.6. Challenges of working with intellectually disabled children

One of the major challenges that teachers face in working with intellectually disabled children is burnout. Teacher burnout occurs when teachers undergoing stress for long periods of time experience emotional exhaustion, depersonalisation, and lack of personal accomplishment (Brunsting, Sreckovic & Lane, 2014). Outcomes associated with burnout include teacher attrition, teacher health issues, and negative student outcomes. Brunsting et al.'s (2014) study alluded that special educators are at high risk for burnout as their working conditions align with many factors associated with burnout. At one point or another, almost all teachers become frustrated with their job or harbour negative feelings toward the profession. Yet, some teachers experience these emotions more acutely or with greater frequency (Nalbant et al., 2013). Teachers were described as experiencing burnout when they stress they encounter their abilities to cope adequately, leading them to feel exhausted, cynical, or unaccomplished in their work.

Brunsting et al. (2013) updated the literature on special education teacher working conditions by reviewing studies that included a quantitative measure of burnout and focused on special education teachers as participants. An analysis of the studies reviewed provided a clear base of support for the association between burnout and a range of variables from the individual, classroom, school, and district levels. Teacher experience, student disability, role conflict, role ambiguity, and administrative support were particularly salient factors in special education teacher burnout.

A study conducted by Ambikile and Outwater (2012) revealed psychological, emotional, social, and economic challenges caregivers endure while living with intellectually disabled children. Psychological and emotional challenges included being stressed by caring tasks and having worries about the present and future life of their children. They had feelings of sadness, and inner pain or bitterness due to the disturbing behaviour of the children. They also experienced some communication problems with their children due to their inability to talk. Social challenges identified in the study were inadequate social services for their children, stigma, burden of caring task, lack of public awareness of mental illness, lack of social support, and problems with social life. The economic challenges were poverty, child

care interfering with various income generating activities in the family, and extra expenses associated with the child's illness.

In a study of parents of children with intellectual disabilities in Vietnam, Shin and Nhan (2009) suggested that the presence of a child with cognitive delay is a predictor of stress among parents. Although there may be other concerns such as lower education, health issues, poverty and reduced social support, the parents consider having a child with cognitive delay as a major source of stress. In fact, lack of economic resources strain the mothers in raising their children, and a father in ill health threatens the financial status of the family when the latter are the main source of income. Similarly, mothers with less education have been found to have fewer strategies in raising children with cognitive delay. Accordingly, families of children with developmental disabilities participate in less family interactions and recreational activities than families who do not have a member with developmental delay. The same study also revealed that high level of stress was attributed to the relationship with the partner. As such, feelings of fear, different responses to the stress of the disability, and the lack of positive affirmations have been linked to marital strain.

According to a study conducted by Hassall, Rose and McDonald (2005), many family respondents felt abandoned by the Tanzanian government that had not fulfilled its responsibility. Participants felt that they were being assisted by outside organisations and there was no allotment of funds from the government. Other families felt deceived that the government had promised them various forms of support but they had so far been unable to access them. In South Africa, an estimated half a million children with disabilities have been shut out of South Africa's education system (Human Rights Watch, 2015). Human Rights Watch (2015) also found that children with disabilities who attend special schools often must pay fees that children without disabilities do not. In some cases, parents are unable to send their children to school because they cannot pay these fees and transportation costs to schools far from their homes (Human Rights Watch, 2015).

2.7. Management of challenging behaviour

Approaches for managing challenging behaviour include psychosocial interventions as well as medication. A survey of psychiatrists suggested that non-pharmacological interventions are the first-choice treatment for aggression where no psychiatric condition is confirmed (Unwin 2008). The consensus was that pharmacological interventions are considered if other treatment is unsuccessful owing to the frequency or severity of the aggressive behaviour, or when there is a risk of harm to self or others. The evidence base for some of these treatment options will be considered here.

2.7.1 Social interventions

Social interventions for challenging behaviour in people with intellectual disability can focus on a range of factors, including level of care, communication and environmental manipulation (Brosnan, & Healy, 2011). For example, nidotherapy (Tyrer 2006) involves making systematic environmental changes (physical, social and personal) to suit the needs of the individual. The aim is to adapt the environment rather than trying to adapt the person. The environmental changes may include alterations to the structural environment, helping the individual to socialise or supporting them in achieving their long-term goals. Nidotherapy offers environmental adjustment rather than direct treatment and at present there is no evidence supporting its efficacy for challenging behaviour in people with intellectual disability (Tyrer 2006).

Active support is another type of social intervention that has been used with people with intellectual disability. Staff receive training in developing person-centred activity plans for those in their care and receive coaching on how to encourage them to engage in activities to deflect them from challenging behaviour. Trials (mainly small case studies) have shown contrasting results, including no effect (Stancliffe 2008), a decrease in challenging behaviour (Toogood 2009) and an increase in challenging behaviour (Bradshaw 2004). Further evaluation of active support is warranted.

2.7.2 Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) has only recently been adapted for people with intellectual disability. At present, evidence from methodologically sound studies is still

scarce for its use as an intervention for challenging behaviour. A Cochrane review of interventions for aggressive behaviour in people with intellectual (learning) disabilities identified just four studies, three using group-based and one using individual CBT with adults, as suitable for inclusion (Hassiotis 2008). Results were variable. Although improvement was reported in emotional distress, anger management and adaptive functioning on both caregiver- and self-ratings, the follow-up periods were short and the studies were subject to bias. More recently, the effectiveness of cognitive– behavioural interventions with this client group was tested in a cluster randomised controlled trial of a 12-week group-based cognitive–behavioural anger management programme delivered by care workers. The findings showed no effect in self-reported anger, but significant improvement in anger as rated by paid and family carers (Willner 2013). The study also demonstrated that the intervention may be delivered by less-qualified staff with reasonable fidelity. Therefore, at present, there is some limited support for the use of CBT as an intervention for challenging behaviour in people with intellectual disability, but further evaluation is necessary.

2.7.3 Mindfulness

Mindfulness, which has its origins in Buddhism, has been described as the focusing of one's attention on present experiences with curiosity, openness and acceptance (Bishop 2004). It has been used for a range of clinical problems and can be used both in conjunction with or as an alternative to behavioural approaches. Mindfulness-based interventions have consistently reported positive outcomes in modifying behaviour. A review evaluating the evidence to date (Harper 2013) identified 18 studies that used mindfulness either as a stand-alone intervention or as part of acceptance and commitment therapy or dialectical behaviour therapy. Ten of these studies recorded effects on aggressive behaviour and all ten reported reduction in aggression. Some of the other positive effects included a reduction in self-injury and injury to staff, reduced self-reports of deviant sexual arousal and a decrease in the management of aggression using medication and restraints by staff. Notably, evidence gained from five of the reviewed studies also suggests that caregivers could successfully be trained to deliver mindfulness-based interventions. However, all the studies were open label and none included

comparison with placebo or another control group. Further support is needed in the form of randomised controlled trials and larger samples in order to establish more conclusive evidence regarding the use of mindfulness in the management of challenging behaviour.

2.7.4 Applied behavioural analysis and positive behavioural support

In essence, the science of applied behavioural analysis involves systematically addressing challenging behaviour using principles of reinforcement and extinction. Since its introduction in the 1960s, the effectiveness of applied behavioural analysis has been illustrated in a large volume of work, including more than 600 studies in the Journal of Applied Behavior Analysis alone (Carr, 2002). One of the more recent studies found that its use by a specialist behaviour therapy team, in addition to standard treatment, produced a significant reduction in challenging behaviour measured by the Aberrant Behavior Checklist and that this positive change was maintained at 2-year follow up (Hassiotis 2008). In its original form, applied behavioural analysis used a range of non-aversive and aversive techniques, but in response to increasing criticism the aversive procedures were abandoned. In the 1980s, applied behavioural analysis took a more person-centred, values-led direction.

This is reflected in techniques such as 'positive behavioural support', an approach that continues to evolve (Carr 2002). Positive behavioural support involves identifying the purpose of the challenging behaviour and working out a support plan that encourages the development of new skills to reduce the individual's need to engage in the behaviour (Carr 2002; Allen 2005). Its focus is on individualised interventions that are based on a clear understanding of the person and the purpose of the behaviour. The interventions aim to develop appropriate social, communication and behavioural skills that enable the individual to replace the problem behaviour with a functionally equivalent behaviour that is more appropriate. It avoids the use of aversive measures such as punishment (e.g. excluding the individual from certain activities) and promotes the use of positive and supportive strategies. The overall aim is to improve the individual's quality of life by enabling them to have positive social interactions and access new environments. Positive behavioural support can be delivered by diverse mediators, ranging from family members

to support workers, but mediators will need to receive training and to be appropriately organised and supported .

A review of 109 articles evaluating positive behavioural support interventions (see Carr, 2002) concluded that 52% of interventions reduced challenging behaviour by at least 90% from baseline levels and 68% by at least 80%. For about two-thirds of the interventions the effect was maintained for between 1 and 24 months. Evidence was also found regarding factors that influence efficacy: interventions were more effective for single than for combinations of behaviours and when they were implemented by the individual's regular carers as opposed to external specialist providers. LaVigna & Willis (2012) concluded that positive behavioural support is effective in institutional settings and in the community. They argue that it is cost-effective and applicable to varying levels of severity and frequency of challenging behaviour. We (A.H. and J.B.) are currently involved in a multicentre cluster randomised trial (NCT01680276) in the UK to investigate the clinical benefits and cost-effectiveness of positive behavioural support.

2.7.5 Pharmacological interventions

2.7.5.1 Antipsychotics

Antipsychotic medications are regularly prescribed to people with intellectual disability and behavioural disorders (Grey 2005). However, there are limited data available on their efficacy in modifying challenging behaviour. One doubleblind randomised controlled trial comparing haloperidol and risperidone with placebo in 86 individuals with aggressive behaviour and intellectual disability found no evidence at 4 weeks that antipsychotics were more effective than placebo (Tyrrer 2009). However, another comparing risperidone with placebo in 77 patients did find evidence at 4 weeks supporting the use of risperidone in participants with mild or moderate intellectual disability or borderline intellectual functioning, and DSM-IV disruptive behavioural disorders (Gagliano et al., 2005). Participants assigned to risperidone showed a significantly greater improvement on the primary outcome (Aberrant Behavior Checklist) as well as improvements on secondary outcomes. The trial continued for another 48 weeks as an open-label study where both groups were continued on risperidone, and further improvements were noted. There is currently insufficient evidence that antipsychotic medication is either helpful or harmful for

adults with intellectual disability and challenging behaviour (Brylewski 2004; Deb 2007a,b,c). This is especially salient in light of the findings of a more recent study on the knowledge and experiences of people with intellectual disability receiving antipsychotics (Crossley & Withers 2009). Its participants had little knowledge about their medication beyond knowing the dosing regimen and generally accepted the side-effects that they were experiencing. It was noted that this compliance was probably because they were used to relying on other people to make decisions, including those about treatment, on their behalf, trusting them to be better placed to do so. There is some evidence for the effectiveness of risperidone in addressing challenging behaviour in children with autism spectrum disorder, including those with intellectual disability (Unwin 2011; National Collaborating Centre for Mental Health 2012). In individuals with autism, antipsychotics may reduce the arousal and anxiety contributing to the challenging behaviour. However, National Institute for Health and Care Excellence (NICE) guidelines state that such medications should not be used to treat core symptoms of autism in adults or children (National Collaborating Centre for Mental Health 2012, 2013), although a randomised controlled trial of risperidone v. placebo indicated a significant reduction in stereotyped behaviours at 6 months (McDougle et al., 2005). An audit of the prescribing of antipsychotic medication in adults with intellectual disability revealed that increased use of such drugs correlated with severity of intellectual disability and challenging behaviour in the absence of comorbid mental illness (Paton et al., 2011).

2.7.5.2 Mood stabilisers

There are two double-blind controlled trials showing beneficial effects of lithium compared with placebo in treating aggression in people with intellectual disability. Tyrer et al., (2006) conducted a 5-month crossover trial involving 25 in-patients, where lithium or placebo was added to existing antipsychotic or anticonvulsant treatment. The study found that 17 patients showed improvement in levels of aggression during the lithium phase compared with the placebo phase. Factors associated with a good response included female gender, a history of epilepsy, a low level of aggression pre-treatment, and the presence of overactivity and stereotypical behaviour. Improvements were less likely in males with very frequent aggressive behaviour. Craft et al., (1987), in a study of 42 patients randomised to

lithium or placebo, found that 16 (73%) of the 22 receiving lithium showed a reduction in aggression over a 12-week period. Side-effects were reported in 8 (36%) of the patients on lithium compared with 4 (20%) on placebo. Most of the participants had not responded to other treatments. Both of these studies have limitations in terms of their sample size, the measures used to assess response to treatment, and lack of follow-up data and applicability in current practice. The participants in the two studies were hospital inpatients, whereas the majority of service users with aggressive behaviour now live in the community, where it is often less practical to initiate lithium. Multicentre randomised controlled trials using lithium are required to provide further evidence of efficacy and safety. A systematic review found little evidence for the effectiveness of mood stabilisers in the treatment of explosive and intermittent aggression (Jones et al., 2011). Although it found some support of their use in reducing the severity and frequency of aggressive behaviours, this was the case only for phenytoin, lithium and carbamazepine/oxcarbazepine, and not for valproate or levetiracetam. However, several of the studies were subject to bias, and when these were excluded, no significant effect in reducing aggression was found for treatment with mood stabilisers. A major drawback is that the review did not include studies involving people with intellectual disability.

2.7.5.3 Antidepressants

Selective serotonin reuptake inhibitors (SSRIs) have been frequently used for the management of challenging behaviour, although the supporting evidence is circumstantial or based on small open-label studies. One review found that antidepressants, SSRIs in particular, produced improvement in aggressive and self-injurious behaviour in people with intellectual disability in less than 50% of cases (Sohanpal et al., 2007). The effect of antidepressants was most apparent in individuals with an underlying anxiety disorder. However, there is some evidence that fluvoxamine may be effective in reducing challenging behaviour in adults with autism spectrum conditions (Oliver- Africano 2009).

Thus, at present there is a paucity of evidence on the effectiveness of pharmacological interventions for challenging behaviour in intellectual disability, with the exception of autism spectrum disorder, where there is limited evidence for the use of antipsychotic

medication. Given concerns about the potential for side-effects, further investigation of such treatments is needed.

2.7.5.4 Current NHS service delivery models

A locally based service model for the management of challenging behaviour in people with intellectual disability has been recommended by several UK government policies (Department of Health 2007; Commission of Social Care Inspection 2009), but progress towards this has been slow (Allen 2005). The behaviour can usually be managed in a community setting with the help of community intellectual disability teams. For individuals presenting with more severe or ongoing challenging behaviour, input from a specialist challenging behaviour team may be helpful, but service provision does vary in different areas. Individuals with intellectual disability presenting with severe challenging behaviour that cannot be managed in the community because of the risk to the individual or others will require admission to hospital. If the person has an underlying mental illness, then where possible, admission should be to a generic mental health ward. However, if the needs are more complex, admission to a specialist hospital for people with intellectual disability (an assessment and treatment or A&T unit), may be required. Following the exposure of widespread physical and emotional abuse at one A&T unit, Winterbourne View hospital, the Department of Health (2012) set out a programme to reform these services. Admission should occur only in exceptional circumstances, the reason should be clearly documented and families should be involved in the decision-making process. The time spent in such units should be brief and should focus on the attainment of specific goals. Out-of-area placements should be avoided as they can have deleterious effects on relationships and continuity of care and may contribute to challenging behaviour. Commissioners are expected to work more closely with local service providers to ensure that appropriate local placements and skilled care are available.

Above all, there is very little support for use of pharmacological treatments for people with challenging behaviour and intellectual disability in the absence of coexisting mental illness. However, medication may be required in the presence of high arousal and severe aggressive behaviour. There is emerging interest in behavioural interventions for reducing challenging behaviour, including positive behavioural support, a values-led approach that

is person centred. The increasing proliferation of treatment approaches for challenging behaviour and the ongoing improvement in study design, including randomised controlled trials, are cause for optimism regarding the enhancement of evidence-based care for individuals with intellectual and developmental disabilities and challenging behaviour.

2.8. Ways of coping with intellectually disabled learners

According to Lazarus and Folkman (1984), coping is constantly changing cognitive and behavioural efforts to manage specific internal and external demands that are appraised as exceeding the resources of the person. Coping can be measured as a disposition which is what people usually do in a particular situation or it can be measured as situational behaviour which pertains to what a person does in a specific situation. Durban, Rodriguez-pabayos, Alontaga, Dolorfino-arreza and Salaza (2012) described coping as behaviour that protects people from being harmed by stressors or life strains. Govender (2002) pointed out that there are stable coping styles or strategies that people bring with them to the situation that they encounter. According to this view, people do not necessarily approach each coping situation anew, but bring to bear a preferred set of strategies that remain relatively fixed across time and circumstances. They argue that although coping strategies are not static, people tend to develop characteristic ways coping.

There are many ways to categorise coping strategies. Coping is identified as being either active or avoidant. Active coping strategies involve an awareness of the stressor, followed by attempts to reduce the negative outcome. By contrast, avoidant coping is characterised by ignoring the issue, often resulting in activities that aid in denial of the problem, for example drinking and isolation (Butcher, Mineka & Hooley, 2014).

According to Brannon, Feist and Updegraff (2013), people tend to use one of the three main coping strategies when dealing with circumstances that may be stressful to them. These strategies are appraisal-focused; problem-focused; and emotion-focused coping. Similarly, teachers of children with intellectual disability may adopt these strategies to cope with the challenges encountered in working with the children:

- Appraisal-focused: This is directed towards challenging your own assumptions. This strategy is appropriate when there is no straight-forward solution to a problem. This occurs when a person modifies the way they think, for example, employing denial, altering goals and values, identifying the humour in the situation to bring a positive spin or distancing oneself from the problem or challenge.
- Problem-focused: Here efforts are directed at defining the problem, generating alternative reactions, weighing the *pros* and *cons* and then take action. People who use this strategy try to deal with the cause of their problem. They do this by getting information on the problem and learning new skills to manage the problem. Problem-focused coping includes two major groups of problem-oriented strategies; those directed at the environment and those directed at the self. The former includes strategies for altering environmental pressure, barriers, resources and procedures. Strategies directed at the self-include behaviours directed at motivational and cognitive changes. Most problem-focused coping strategies are situation-specific and not as generalised as emotion-focused coping (Lazarus & Folkman, 1984).
- Emotion-focused: This may involve a number of activities such as releasing pent-up emotion, distracting oneself, managing hostile feelings, meditating or using systematic relaxation procedures. Emotion-focused coping strategies are directed at regulating the emotional response to a problem. One large group of these responses involves cognitive processes directed towards lessening emotional distress and includes strategies such as avoidance, minimisation, selective attention, positive comparisons and wresting positive value from negative events.

A number of studies have pointed out that those who live or work with intellectually disabled people tend to resort to a number of coping strategies (Jacobs, 2006; Pilusa, 2006), including the three strategies identified above by Brannon et al. (2013). One such coping strategy is the inclusion of educational psychologists in special schools. A study by Rothia, Leavey and Best (2008) focused on teachers' perceptions and experiences of working with educational psychologists in order to support those pupils who cause concern about their mental well-being. Many of the barriers highlighted could be traced back to a perceived shortfall in the length of time educational psychologists spend in

schools working with pupils, school staff and parents. Other important issues emerged that require consideration if they were to move towards a more holistic system that provides for children's educational, health and social care needs in an integrated manner.

Clearly, educational psychologists are highly valued by special school teachers (Rothia et al., 2008). However, there are a number of issues that teachers believe constrain service provision such as substantial under-funding. Although teachers' favours the allocation model, most teachers believe that the allocation level is unrealistically low, resulting in a lack of direct hands on interventions with children in the classroom. This would leave the teachers struggling to cope in the classroom and feeling unable to implement many good and potentially useful strategies that have been suggested by psychologists. Moreover, in an inclusive education system it is disappointing to find out that some schools believe that the only way they can cope with very challenging children is to unofficially exclude them from learning (Rothia et al., 2008).

Parents experiencing stress often adapt coping strategies in handling stressful situations. Thus, coping involves efforts and strategies aimed to manage stress, regardless of how it works. Coping strategies involve efforts to face the stressful situation. Fielder, Simpson and Clark (2007) indicated that stress may be manifested biologically (fatigue, exhaustion, cardiovascular strain, reduced immune response, headaches, gastrointestinal upset, decreased appetite, and vulnerability to illness), psychologically (cognitive and emotional effects such as shock, terror, irritability, anger, guilt, grief, helplessness, impaired concentration, confusion, decreased self-esteem, and decreased self-efficacy) and socially (the disruption of a social unit such as a family). In order to deal with this stress, parents resort to biological means such as taking medication, psychologically they seek counselling and psychotherapy and socially they seek family support.

The importance of family coping with the stress they experience in having a member with disability often relies on the parents. Hence, how the parents cope with the stressful situation will dictate how the child with disability will be provided services needed for his or her development. Judge (1998) posited that parents use a variety of different styles in coping strategies. She also noted in her study that 58% of the coping strategies used by

parents were problem-oriented while 42% of the possible coping strategies were emotion-oriented.

2.9. Psychological interventions

2.9.1 Behavioural interventions

While there is substantial evidence that lends credence to the efficacy of behavioural intervention in the form of differential reinforcement and the use of functional assessment to reduce or mitigate problem behaviour among people who have ID, the preponderance of behavioural research in this area mostly consisted of single case designs or small controlled and non-controlled ABA designs that were not randomised (Chowdhury & Benson, 2011).

Positive programming has gained recognition as an important behavioural intervention that is widely applied to manage problem behaviour including aggression (Matson et al., 2012; Kushlick et al., 1997; McClean & Grey, 2012). Positive programming consists of a functional analysis and the employment of differential reinforcement that uses positive reinforcement and extinction to decelerate undesirable behaviours (McClean & Grey, 2012). The use of stimulus control and crises intervention strategies has also been successfully employed to mitigate the risk of acute behavioural outbursts (Kushlick et al., 1997).

2.9.2 Cognitive-behaviour therapy

Cognitive-behaviour therapy (CBT) is increasingly used to address problem behaviour among persons who have ID (Bhaumik et al., 2011; Jahoda, Dagnan, Stenfert Kroese, Pert, & Trower, 2009). A recent review has identified smaller studies that demonstrated the usefulness of CBT in the treatment of psychiatric disorders such as depression and anxiety (Bhaumik et al., 2011). The successful psychotherapy treatment of psychiatric conditions may also have a positive impact on the management of problem behaviour if there is a clear relationship between the two variables (Allen & Davies, 2007; Royal College of Psychiatrists, 2001). As is the case with pharmacological treatment and behavioural intervention, there is a need for larger, randomised-controlled trials to establish the efficacy of CBT with people who have ID and problem behaviours (Bhaumik

et al., 2011; Whitehouse, Tudway, Look, & Kroese, 2006; Willner, 2008). In this regard, two randomised control trials on anger management have provided promising evidence of the effectiveness of CBT among adults who have ID (Bhaumik et al., 2011; Taylor, 2002; Willner, Jones, Tams, & Green, 2002).

2.9.3 Low-arousal approaches and the management of aggression

Low arousal approaches (LAA) are relevant to the current study because many of the theory's underlying tenets were incorporated into the therapeutic agendas of participating mothers. LAA describe non-aversive strategies to manage aggression among persons who have DD (McDonnell, 2010). LAA separate the management of aggression from its treatment: whereas treatment attempts to reduce the frequency, severity or duration of aggression, LAA attempt to manage the behaviour with the explicit goal of risk mitigation. Stated differently, LAA primarily attempt to ensure the safety of caregivers and the persons who display aggression regardless of whether such behaviours persist or not (McDonnell, 2010).

Aggression is conceptualised as the result from the reciprocal interaction between caregivers and persons who have ID (McDonnell, 2010). The emotional distress of caregivers could therefore have a direct impact on the escalation and maintenance of aggressive outbursts among persons who have ID. McDonnell (2010) accordingly recommends that caregivers should become aware of their own trigger points and agitation during crisis situations. LAA employ strategies to de-escalate such crisis situations in a non-invasive manner, including arrangements to set-up a low arousal environment. Parents and paid carers are also sensitised to the reciprocity of arousal between themselves and their child or service user (McDonnell, 2010).

2.9.4 Psychodynamic approaches when working with children and adults who have ID

Psychodynamic approaches in the disability field have provided valuable insight into the emotional lives of children and adults who have disability (Capri & Buckle, 2015; Watermeyer & Swartz, 2016). Psychoanalytic perspectives recognise that societal restrictions and unavailable or inadequate utilitarian resources may have a disabling

impact on a person, e.g., the absence of sign language interpreters in an organisation that renders services to people who are deaf (Watermeyer & Swartz, 2016). Psychodynamic literature also describes an internal, psychological response to disability and the disabling aspects of stigma, perceived difference and the social marginalisation of individuals who have disability (Sinason, 2010; Watermeyer, 2016). Valerie Sinason (2010) has used the concept of secondary handicap to describe a person's reactions in dealing with a primary handicap or intellectual disability. Such reactions generally present in the form of defence mechanisms against unconscious anxiety or the emotional pain that is evoked by the primary handicap (Sinason, 2010).

The realisation of difference or “otherness” may also evoke feelings of emotional pain among persons who have disability (Watermeyer & Swartz, 2016). The painful realisation of your own limitations is not restricted to persons who have disability. As Sinason (2010) argues, adolescents and young adults have the developmental task of reconciling their unfolding ideals, dreams, aspirations and hope of the future with the limitations of their own intellect, talents and physical attractiveness:

Opening your eyes after adolescence to the realization that you will not be an Austen, Einstein, Madonna or Picasso can be painful enough to the ordinary adolescent. Opening your eyes to admitting you look, sound, walk, talk, move or think differently from the ordinary person, let alone a cult hero or heroine, takes greater reserves of courage, honesty and toleration of one's own envy (p. 18).

Persons who have ID may present with a mild secondary handicap that is characterised by efforts to lower their intelligence or communication abilities. Ironically, a person who has a mild secondary handicap often resorts to efforts of “exacerbating their original handicap to keep the outer world happy with them” (Sinason, 2010, p. 18). Opportunist secondary handicap represents a more pronounced psychological reaction that is characterised by maladaptive personality development as a defence against the same painful knowledge of being different in a perceived adverse manner. Secondary handicap may also result from exposure to traumatic events in the person's life, and in such instances the secondary handicap acts as a defence against painful and traumatic memories of such events (Sinason, 2010).

Without negating the role of disabling external factors that perpetuate disability, psychoanalytic therapy construes many of the behavioural difficulties among persons who have ID as the result of their secondary handicap (Sinason, 2010). Therapists engage with persons who have ID in the containing space of the therapeutic relationship. Psychoanalytic therapists recognise that these individuals have emotional richness notwithstanding their intellectual impairment. Psychotherapy is therefore employed to lessen the impact of the secondary handicap in the person's life (Sinason, 2010).

In the context of the present study, it is important to note that the parents of children who have ID may also be affected by the same trauma that led to the formation of a secondary handicap in their offspring (Sinason, 2010).

2.10. Culture and intellectual disability experience

Intellectual disability is a complex label involving interactions between biogenetic and sociocultural factors. The diagnostic criteria are the significant and enduring impairment in social and intellectual functioning evident before adulthood. Deciding on the presence or absence of learning disability requires an arbitrary line to be drawn across a continuum of ability. One measure is the IQ test, yet this was once used to prove the innate inferiority of immigrant populations. Eminent psychologists such as Arthur Jensen and Hans Eysenck supported claims that differences in IQ ratings between 'White people' and 'coloured, primitive people' were due to race, although this view is now strongly opposed by many (Fernando, 2012). The cultural bias of IQ testing is well recognised but it is still administered in a culture-blind fashion. Cultural bias in verbal tests is obvious, but there is no guarantee that non-verbal tests are free from bias (Fernando, 2012). How well children with mild intellectual disabilities do in school or in adult life and, indeed, how they come to be diagnosed in the first place, largely depends on social and cultural conditions. This type of intellectual disability has been called 'sociocultural' or 'reversible' to emphasise the importance of social and cultural factors.

Traditionally, medical anthropologists have displayed an interest in the role of socio-cultural factors in health and illness (Kleinman & Benson 1997). Cultural factors are increasingly recognized as important determinants of not only intellectual disability

management and treatment but also psychological and behavioral outcomes following diagnosis (Halbert et al., 2007). Culture is defined as a set of shared and socially transmitted ideas about the world that are passed down from generation to generation (Koltko-Rivera, 2004). Culture as a socially transmitted phenomenon carries with it the idea that people who interact on a regular basis know the same unwritten rules and criteria for social life. Within this overarching framework, the construct of world view is used by social scientists to describe beliefs and values regarding the nature of time (e.g. present, future), social relationships (e.g. individualism, collectivism), and the presence or absence of natural and supernatural entities (e.g. materialism, spiritualism) that are shared among members of ethnic and racial groups (Koltko-Rivera, 2004).

Culture therefore is a pattern of ideas, customs and behaviours shared by a particular people or society. It is dynamic, yet stable. Health is a cultural concept in that culture frames and shapes how we perceive, experience and manage health and illness. In 2010, the World Health Organization broadly defined health as a state of complete physical, mental and social well-being. Different cultures view health in different ways. For example:

- In Western medicine, health is mainly seen as an absence of disease, with focus on biological aspects of life.
- *Ayurveda*, an ancient Indian system of medicine, views health as a harmony between body, sense organs, mind and world.
- Traditional Chinese medicine sees health as a balance between yin and yang, or the 'hot' and 'cold' qualities of an individual.

WHO (2015) referred to the importance of socio-cultural factors by endorsing the following view:

“Psychological factors have been increasingly recognized as key factors in the success of health and social actions. If actions are to be effective in the prevention of diseases and in the promotion of health and well-being, they must be based on an understanding of culture, tradition, beliefs, and patterns of family interactions”.

All cultures have disease theory systems which include attributional concepts to explain illness causality (Koltko-Rivera, 2004). Illness representations may be presented according to symptom perception/cultural beliefs; perception of the chronicity of the illness; the physical and the emotional influences of the illness; cause and effect perceptions; and potential for cure (Kleinman, 1997). According to Uskul (2010), illness representations are organised sets of beliefs regarding illness labels or diagnosis. These illness representations may include different disease models, wellness/illness paradigms, and the use of traditional and indigenous healthcare practices and approaches. African patients may be more likely to attribute illness to a metaphysical or social cause rather than a physiological or scientific cause (Vaughan, Jacquez & Bakar, 2009). For example, one study found that Chinese were more likely to attribute mental illness to cosmic or supernatural causes (Vaughan et al., 2009). Another research study on cross-cultural evidence on intellectual disabilities indicates that some Tanzanian people believe that intellectual disability is a curse or a burden to a family, persons with intellectual disabilities around the world are excluded, shunned, and hidden from communities. (Iseselo, Kajula & Yahya-Malima, 2016).

Personalistic disease theory, on the other hand, attributes illness to intervention by an agent such as another human being, as in witchcraft, or supernatural forces. A supernatural force may be a dead ancestor (Vaughan et al., 2009). Recovery from an illness arising from personalistic causes usually involves the use of ritual, most often performed by indigenous practitioners who are especially trained in these arts. Emotionalistic disease theories explain illness as caused by strong emotional states, for example, intense jealousy, anger, or shame (Vaughn et al., 2009). People of African descent are more likely to use personalistic and emotionalistic theories to explain illnesses.

2.11. Spirituality/religion and intellectual disability

Spirituality is difficult to precisely define and measure, but there is general agreement that it refers to a connection with a larger reality that gives one's life meaning, experienced through a religious tradition (Balboni, Sullivan, Amobi, Phelps, Gorman, Zollfrank & Balboni, 2013). It is considered to be a complex, multifaceted, construct that manifests in

the process of an individual's behaviour, beliefs, and experience (Pargament, 1997). According to Park and Folkman (1997), spirituality can operate at several levels of the stress and coping process. It can function at the level of person (e.g. beliefs), primary and secondary appraisals (e.g. God attributions), coping behaviour (e.g. prayer), coping resources (e.g. connection to nature), and meaning making (e.g. spiritual appraisal) (Pargament, 1997). According to Mattis (2005), religion is a system of symbols which acts to establish powerful, pervasive, and long-lasting moods and motivations in human beings by formulating conceptions of a general order of existence. It organizes the collective spiritual experiences of a group of people into a system of beliefs and practices. Religious involvement, or religiosity, refers to the degree of participation in, or adherence to, the beliefs and practices of an organized religion (Mattis, 2005).

Flowing from this definition, religion can be perceived as a formal system of beliefs held by a group of people who share certain perspectives on existence and the nature of the world. These perspectives are communicated through shared practices, beliefs, and ritual (Cheyney, 2011). Religion incorporates ways in which people see and interpret the world around them and make sense of their experiences within that world. This interpretation shapes and impacts on the ways in which illnesses are perceived and responded to by individuals and by communities. (Samovar, Porter, McDaniel & Roy, 2015)

2.11.1. Spirituality and health

An increasing body of knowledge suggests that the development of spirituality is important in maintaining personal physical and mental health and well-being. Treloar (2002) notes that a person's beliefs can influence his or her response to life. She quotes John, a young man with cerebral palsy, who says that 'one of the main things my faith has done, it's kept me alive'. He says that it has helped him cope with the difficulty of having a disability. Indeed, faith seems to help many people with disabilities and their families to respond positively to life's difficulties and also to understanding the disability itself.

2.11.2. The role of religious communities

Religious communities can facilitate the community involvement for people with intellectual disabilities; they can provide networks of friends and supporters, and enable

people with disabilities to participate in social and personal relationships in the life of the church or spiritual group (Davidson, Chinman, Kloos, Weingarten, Stayner & Tebes, 1999). However, difficulties also exist. Some religious groups require clear statements of faith which people with intellectual disabilities may be unable to give (Cheyney, 2011); others present theological hurdles to accepting the full personhood of people with disability. Certainly there is little evidence that Christian churches engage fully with the issue of disability (Treloar 2002), perhaps because of the few references to disability in the Bible or to a general lack of knowledge of disability. While much support seems to be forthcoming from faith communities, this seems to emanate from individuals rather than from the theological roots of the different religions.

2.11.3 How do people with intellectual disability conceive their spirituality?

Cheyney (2011) conducted interviews and focus groups with people with intellectual disability about their spiritual life. Many of them saw God in personal terms, conceived as a friend who provided support and understanding in the person's life. Potter (2002) notes that many people with intellectual disability have a confidence in their relationship with God and an intuitive feeling for spiritual truths, whereas Treloar (2002) sees a relationship with God as bringing about healing acceptance and enabling coping. None of the studies reviewed here described how a humanistic non-religious approach to spiritual development might be of relevance to a person with an intellectual disability; neither was the role of other, non-Christian faiths considered.

The majority of people in South Africa are Christians. According to figures on religious demographics from the 2001 census, approximately 84% of the population in South Africa belongs to the Christian religion (Statistics South Africa [Stats SA], 2003). Religion plays an important role in the lives of many South Africans. Religion may provide a powerful force for shaping how a teachers and parents of persons with intellectual disability understand their challenging behaviours and the options they perceive they have to be able to respond to the experience. The particular ways in which religion seems to impact on the experience of parents and caregivers of persons with intellectual disability is providing ways of making meaning out of the experience and enabling effective coping. Mattis (2005) found that spiritual practices such as prayer, perceived dependence on God

to intercede and guide, coupled with support from faith communities were used effectively. Social support provided by a faith community may have a buffering effect on the patient faced with the ambiguity of the present and the many uncertainties about the future, parents and caregivers of persons with intellectual disability may rely on their religious beliefs as a source of strength and hope. Religion offers meaning to fundamental existential questions about life, death, and health attributions (Mattis, 2005). Additionally, religion seems to provide positive sense of meaning and purpose to situations that can easily be perceived as deeply meaningless (Cheyney, 2011).

Religious beliefs and practices are commonly used by many patients to cope with mental illness (Mattis, 2005). For example, religious values such as faith in God and concerns among family members were found to be important among mothers of persons with ID (Pargament, 1998). According to Thune-Boyle, Stygall, Keshtar, and Neuman (2006), religious resources may be particularly relevant when dealing with situations involving an element of personal threat such as diagnosis of intellectual disability. This reframing and meaning-making capacity of religion, however, is not always positive. For example, Mattis (2005) argue that some individuals may have negative modes of coping such as feeling abandoned by God or angry with God leading to diminished quality of life. Patients with this kind of religious mind-set will fare poorly in coping with challenging behaviours of intellectual disability.

2.11.4. The role of spirituality in the future for people with intellectual disability

The first lesson to emerge from this brief consideration of the literature is that recognition of the importance of a spiritual dimension to people with an intellectual disability seems to be of relevance to those who are concerned with the provision of holistic care. Secondly, religious institutions need to be encouraged to include people with disabilities in their life, and to further the search for meaning in relation to explaining and understanding disability (Treloar 2002). Cheyney (2011) suggests that fundamental changes in both society and in religious institutions are necessary in order for spiritual care to become a positive factor in personal support. This represents another change that must be faced among all those now occurring in religious life in Ireland. It is also a chance for religious communities to offer a positive outreach to people with disabilities that can benefit both groups.

2.12. Conclusion

The literature reviewed above indicates that socio-cultural factors are increasingly becoming important in intellectual disability. The area of cultural beliefs and its impact on the challenging behaviours of persons with intellectual disabilities is under researched despite evidence that how illness and disease is explained often varies from culture to culture, society to society and person to person. People of diverse cultural backgrounds often make different attributions of illness, health, disease, symptoms and treatment. Different cultural groups have diverse belief systems about health and healing in comparison to the mainstream Western biopsychosocial model of behaviour. These belief systems may include different disease models, various culturally-specific diseases, seeking Westernized healthcare, and the use of traditional and indigenous healthcare practices and approaches. A key piece currently missing in the intellectual disability literature is the role of cultural beliefs in psychological interventions on managing challenging behaviours of persons with intellectual disabilities. The literature on challenging behaviour and lived experiences of parents and teachers of persons with intellectual disabilities, lack ways of proposing of developing cultural competence models in the delivery of care to persons with intellectual disabilities. The next chapter presents of the theoretical framework underpinning the study.

CHAPTER 3

CONCEPTUAL FRAMEWORK

In this chapter, the theoretical framework underpinning the study is presented. In the first part of the chapter, the Bio-psychosocial theory as one of the frameworks chosen for the study is discussed. Firstly, the conceptual basis of the Bio-psychosocial theory is outlined. Secondly, the evaluation of the BPS theory is presented followed by the assumptions of the Bio-psychosocial theory. Thirdly, the discussion of the advantages, disadvantages and criticisms of the model are presented. In the second part of the chapter, the Afrocentric paradigm, as one of the frameworks chosen for the study is discussed. Finally, the rationale for combining the Bio-psychosocial theory and the Afrocentric paradigm as the theoretical framework for the study is presented.

3.1 The Bio-psychosocial (BPS) Theory

The bio-psychosocial theory emphasises the interplay of biological (genetic predisposition), psychological or behavioural (lifestyles, explanatory styles, health beliefs), and social factors (family relationships, socioeconomic status, social support) in the explanation of pathogenesis and health aetiology (Bowling, 2014). This theory explains that all the three domains play an equal part in the manifestation of all the health situations, and that none of them may be used in isolation to explain any patient or pathology with the exclusion of the other two (WHO, 2007). This model was also an alternative to the biomedical theory that was in wide-spread use at the time and is still the dominant healthcare theory. The theory provides a blueprint for research, a framework for teaching, and a design for action in the real world of health care. This theory further asserts that the determinants for, and the prognosis of, mental health difficulties are the result of an interaction between biological, psychological, and social factors (Babalola, Noel & White, 2017). The researcher will also use George Engel's Bio-psychosocial theory to understand how teachers and parents understand the challenging behaviour conditions reflected by persons with intellectual disabilities.

The 'bio' component of this theory examines aspects of biology that influence health.

Mental health professionals and medical practitioners classify these intellectual impairments and causes of intellectual disabilities in these ways: (Sarafino & Smith, 2014)

- **Genetic conditions** – intellectual disabilities caused by genetics derive from abnormal genes. Parents may pass these abnormal genes on to children or errors could arise when genes combine in the womb that causes intellectual disabilities (Dacey, Lennon & Fiore, 1998). Abnormal genes can occur from infections during pregnancy or from things like overexposure to radiation from X-rays. The intellectual disabilities associated with several genetic diseases, such as:
 - *Phenylketonuria* (PKU) – a genetic disorder caused by a missing or defective enzyme. Children with PKU cannot process a protein known as phenylalanine. Without proper care and treatment, phenylalanine builds up in the blood causing intellectual disability (Blau, (2016).
 - *Down syndrome* – a chromosomal disorder. These types of disorders occur randomly; too many or too few chromosomes cause these conditions. Sometimes a change in the structure of a chromosome can cause these disorders (Nussbaum, McInnes, & Willard, 2015).
 - *Fragile X syndrome* – a gene disorder located on the X chromosome. Fragile X syndrome represents one of the leading causes of intellectual disability (Blau, N. (2016).
- **Pregnancy issues** – pregnant mothers who use alcohol or drugs during pregnancy put their developing babies at risk for intellectual disability (Carpenter, Blackburn & Egerton, 2014). In fact, one of the best ways to decrease the risk of intellectual disabilities involves completely avoiding alcohol during pregnancy. Smoking during pregnancy can also increase the risk that a baby will have an intellectual disability (Newman & Newman, 2017). Carpenter, Blackburn and Egerton (2014) alluded that their risk factors during pregnancy include; *malnutrition, environmental toxins* (i.e. mercury, lead), *infections of the mother*, toxoplasmosis, cytomegalovirus, rubella and syphilis.

- **Issues during birth** – premature birth and low birth weight represent risk factors and often indicate more serious problems to come. Sometimes oxygen deprivation or other injuries occur during the birthing process and subsequently causes intellectual disabilities (de Tella et al., 2016).
- **Problems after birth** – sometimes childhood diseases can damage the brain causing characteristics of intellectual disabilities. Further, injuries like a head injury or near drowning can cause a child to develop intellectual disability symptoms (Carpenter, Blackburn and Egerton 2014).
- **Illness or injury.** Infections like meningitis, whooping cough, or the measles can lead to intellectual disability. Severe head injury, near-drowning (van Timmeren, van der Putten, van Schrojenstein Lantman-de Valk, van der Schans, & Waninge, 2016).

The 'psycho' component of the theory examines psychological components, things like thoughts, emotions, or behaviors (Greene, 2017).

Adverse experiences in early life affecting development of personality, confidence, self-esteem, coping strategies and traumatic experiences at any stage of life

- Identification of learning experiences affecting parent-infant bonding and family dynamics
- Childhood spent outside a family home, e.g. hospital, residential school, children's home
- Lack of consistent parenting and special one-to-one relationship
- Repeated broken relationships, e.g. hospital care, multiple moves between foster homes
- Childhood and adult exploitation, neglect, abuse
- Bullying, harassment
- Experiences resulting in long-term difficulties establishing trusting confiding relationship, low self-esteem, low confidence, limited coping strategies

The 'social' component of the BPS theory examines social factors that might influence the health of an individual, things like our interactions with others, our culture, or our economic status (Wells, Evans & Cheek, 2016).

- **Poverty and cultural factors** – children who live in poverty have a much higher risk of exposure to environmental toxins, diseases and experiencing extreme malnutrition, infections in the brain, exposure to toxic substances such as lead, and severe neglect or abuse can also cause it. These things all increase the risk that a child may develop characteristics of intellectual disabilities. Also, those living in poverty may miss out on important cultural and educational experiences available to other kids.
- **Life events** are often multiple: e.g. death of mother often results in a change in residence + change in day centre + move from familiar neighbourhood + loss of previous social network + intimate care now provided by a stranger + sharing a home with new people.
- **Limited social networks** - Limited choices and opportunities, poverty of environment, problems accessing transport and Limited one-to-one attention.
- **Social exclusion** - Repeated pattern of broken relationships (support workers retire, move, are promoted, change job, take maternity leave). They also suffer from exploitation and abuse; stigma and carer strain.

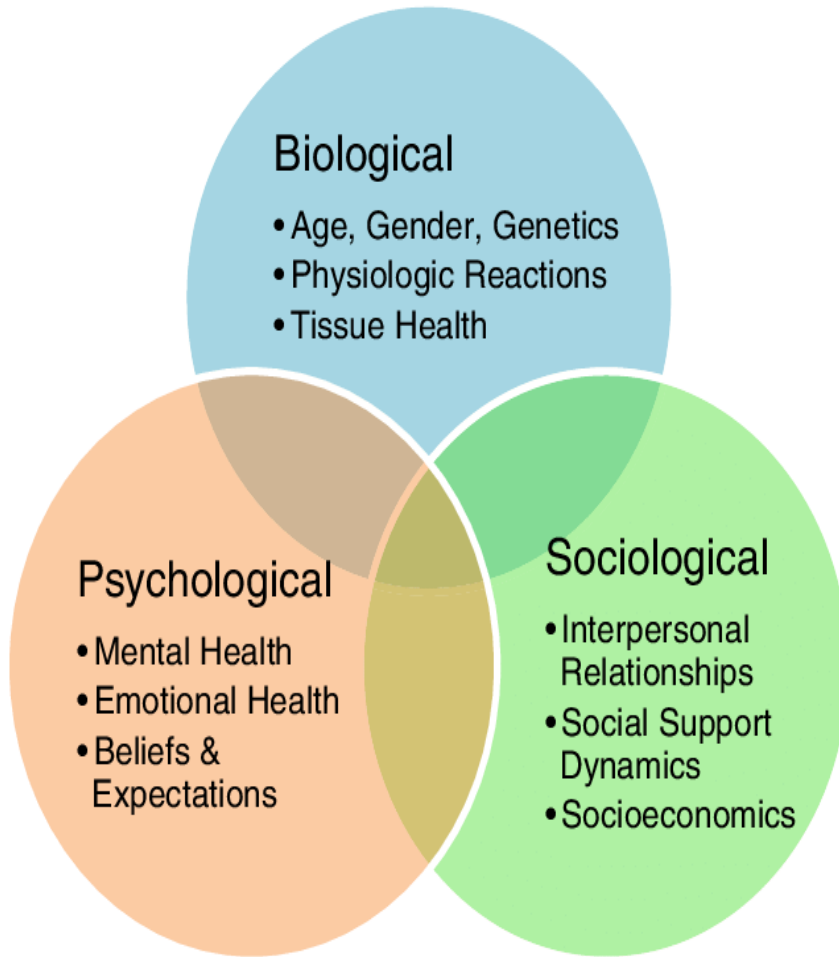


Fig 1: Diagram of the Bio-psycho-social theory by Glied et al. *Chiropractic & Manual Therapies* (2017) 25:16

3.1.2 The conceptual basis of the BPS

The Bio-psycho-social (BPS) model proposed by Engel four decades ago was regarded as one of the most important developments in medicine and psychiatry in the late 20th century. Unlike the biomedical theory, the BPS theory posits that biological, psychological, and social factors play a significant role in disease causation and treatment. This theory brought about a new way of conceptualizing mental health difficulties and engendered changes within research, medical teaching and practice. (Engel,1977).

The Bio-psychosocial (BPS) theory was proposed as a necessary change from the biomedical theory in which health was the result of the absence of disease, and where illnesses and treatment options were understood within a physiological framework (Babalola, Noel & White, 2017). Under the biomedical theory illnesses were understood as having physiological aetiologies that were diagnosable through distinct biochemical markers, and were to be treated via physical interventions. Engel highlighted how, in order to reassert its position as a medical discipline, psychiatry in the mid-19th century adopted the biomedical theory, reducing mental health difficulties to brain diseases that needed treated via pharmacological interventions targeting biological disturbances (Fava & Sonino, 2017). Engel claimed that this had culminated in a crisis developing within medicine and psychiatry, where doctors were failing to fulfil their “scientific task” as well as their “social responsibility” (Babalola, Noel & White, 2017).

In short, he argued that the “Western folk theory of disease” based on a dualistic understanding of the mind and body had merged with the biomedical scientific theory, becoming more dogma-like than scientific. In being myopic to the psychosocial dimensions of disease and reducing illness to somatic parameters medical practitioners were not only neglecting important determinants of health, but also failing to fulfil their social duty of care. He described the biomedical institutions as “cold and impersonal” and physicians who practiced biomedicine as being preoccupied by procedures and insensitive to the personal problems of the patients and their relatives.” Drawing on the general systems theory from biology, the BPS theory understands illness (as well as patient hood) as emerging from an individual who is part of a whole system composed of “sub-personal levels” (i.e., nervous system, organs, tissues, cells, etc.) and “supra-personal levels” (i.e., individuals living in a psychosocial context) (Babalola, Noel & White, 2017). According to the BPS, the determinants for, and the prognosis of, mental health difficulties are the result of an interaction between biological, psychological, and social factors—with no factor having a “monopoly” on the explanation and/or cure. For example, a person with a major depressive disorder may have challenges at work and difficulties coping within the family (Babalola, Noel & White, 2017). These psychosocial issues may perpetuate the mental health condition (Henningesen, 2015).

3.1.3. Evaluating the contribution of the Bio-psychosocial theory

At the end of the 20th century the BPS theory inferred some important advantages, e.g., in changing the way of conceptualizing “illness,” opportunities existed for holistic and integrative in their approach to illness, and humanistic in the delivery of health care (Edwards, Dworkin, Sullivan, Turk & Wasan, 2016). Individuals with health challenges were now acknowledged to be active participants in the recovery process and good health, rather than mere passive victims of deviations in physiologic functioning. The BPS theory exerts a significant influence on contemporary understanding of mental health difficulties (Ghaemi, 2015). For example, the American Psychiatric Association and the American Board for Psychiatry and Neurology recommend the BPS approach (Babalola, Noel & White, 2017). Babalola, Noel and White (2017) alluded that the model also features predominantly in widely used medicine textbooks such as *Human Behavior* and *Clinical Psychiatry*, by Stoudemire attesting to the fact that the allures of the model remain true today.

It has been claimed that the BPS theory has contributed to a reduction in the mind-body split that has been prominent in Western medicine. This has helped to foster opportunities for mental health services to be integrated into the primary care sector and for mental health researchers to broaden the scope of their investigations (Babalola, Noel & White, 2017).

Under the biomedical theory, emphasis was placed on researchers identifying potential biochemical markers of a disorder: the dopamine hypothesis for schizophrenia, and the serotonin hypothesis for depression are widely known examples. Unfortunately, the evidence in support of definitive biomarkers for mental health difficulties remain elusive. The BPS theory brought additional factors under scrutiny including the contribution that psychological processes (e.g., brooding) and/or social conditions (e.g., interpersonal difficulties) made to the emergence and maintenance of mental health difficulties (Shelton, Barta, Trestman & Wakai, 2016). The efforts were extended from a focus on what mechanisms were underlying the individual’s presentation (i.e., the “how”) to incorporate explorations of the conditions that give rise to it (i.e., the “why”) and to how these relate to each other (Fava & Sonino, 2017). This helped to stimulate cross-disciplinary avenues in mental health research and a focus on hitherto under-researched forms of distress such as

psychosomatic conditions. It is claimed that this new approach to researching mental health difficulties provided a more nuanced and comprehensive understanding of mental health determinants. This included a specific focus on the doctor-client relationship.

As part of the client's social environment, the doctor needs to develop an awareness of how his/her interaction with the client may influence the prognosis of the ailment, and indeed, the BPS theory engendered "client-centered" approaches and a renewed emphasis on the importance of the doctor-client relationship (Smith, Fortin, Dwamena & Frankel, 2013). It allows for a multidisciplinary approach to treatment of mental health difficulties. It permits psychiatrists, psychologists, social welfare officers, psychiatric nurses, occupational therapists, and others in the healthcare team to participate in patient care. This may ultimately lead to better quality of life for the service user. Unlike the biomedical theory that aims to provide "one care suits all" approach, the BPS theory is designed to suit each individual's needs as his/her social and psychological environment is taken into consideration (Lewis, 2007).

The conceptual influence of the BPS theory has spread outside the realms of medicine and psychiatry, and has highlighted that health is more than merely the absence of disease given that the psychological and social dimensions had to be accounted for rather than purely the physical (Fava & Sonino, 2017). This idea has been endorsed in many academic domains such as health education, health psychology, public health, and preventive medicine as well as in public opinion. The BPS theory is today the "conceptual *status quo*" and underpins the World Health Organization's (WHO) definition of health: "A state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity." With the BPS advocating a more comprehensive understanding of determinants of mental health, the responsibility of care has stretched beyond the responsibility of mental healthcare professionals alone, requiring the collaboration of diverse professionals operating at the macro-, meso-, and micro-levels (Babalola, Noel & White, 2017). Therefore, Engel's BPS theory has allowed for a conceptually more holistic understanding of mental health difficulties; broadening not only the awareness of diverse determinants of mental health, but also the responsibility towards its care. However, the theory is not without shortcomings and

the extent to which Engel's theory has succeeded in bringing about a "new medical paradigm" has been debated.

3.1.4 Assumptions of Bio-psychosocial theory

The fundamental assumption of the Bio-psychosocial theory asserts that health and illness are consequences of the interplay of biological, psychological, and social factors where emphasis of the importance of an effective patient-practitioner relationship is critical as patients play an important role in their diagnosis. It is much more difficult to control through experimentation as a direct result of the many variables associated with the psychosocial needs of a patient. Since the Bio-psychosocial theory asserts that health and illness are caused by multiple factors and produce multiple effects, it is critical to utilize an interdisciplinary team approach in diagnosis which provides focus on all aspects surrounding biological, psychological, and social factors. In doing so, a systems approach allows for evaluation of all facets of a patient's environment addressing everything from cellular to societal implications of health and wellness (Suls & Rothman, 2004). The assumptions of the Bio-psychosocial theory of health are that it is holistic as it looks at the whole person and not just the physical side of health, and that it takes into account the environmental aspects of a person's life.

3.1.5 Advantages of the Biopsychosocial Theory

The Bio-psychosocial theory claims that three factors influence health, healthcare, and disease, which are physiological, psychological, and social (Brannon, Feist & Updegraff, 2013). This means that it takes into consideration the smaller picture of any biological problems at an individual level, as well as the bigger picture of psychological issues and the effect society has on that individual and on his/her situation. Hence, this model takes both the micro as well as macro viewpoints into consideration when analyzing a patient. This helps in administering better treatment, say advocates of the model (Ghaemi, 2010).

The Bio-psychosocial theory does not consider health to be a deviance from some constant physiological state. Instead, it emphasizes on health and illness being a result of social, psychological as well as biological factors interacting together (Ghaemi, 2010). Hence, this medical approach does not treat health just from the physiological point of view, but

concentrates on having healthy all-round development, cure, and maintenance of all three factors.

Another advantage of the Bio-psychosocial theory is that cure, recovery, and good health are not completely in the hands of medical experts, but are in fact, partly in control of the patients themselves (Brannon, Feist & Updegraff, 2013). Along with medical experts taking care of the biological treatment, patients and their families can maintain a demeanor that will result in quick psychological and social recovery, which will ultimately help better and faster physiological recovery. When using this medical approach, patients rarely feel helpless or out of control (Ghaemi, 2010).

Since the Bio-psychosocial theory does not believe that disease and illness is caused only because of viruses or bacteria, it promotes better psychological conditions and better social interaction. Similarly, it advocates social support, leading to a promotion of community-based living in society. This in turn affects the general well-being of society at large for the better (Lewis, 2007).

The biomedical theory does not contain any concrete explanation for diseases that are caused without any apparent physiological reason, i.e., psychosomatic disorders. However, the Bio-psychosocial theory, analyzing the interaction between the three major factors in detail, can explain how and why psychological disorders, or social factors can sometimes result in physiological problems (Brannon, Feist & Updegraff, 2013).

The Bio-psychosocial theory advocates for good mental and emotional health in order to maintain a healthy lifestyle. Controlling our mental health as well as the effects society can have on us, is in our hands, and if successful, it can help in disease prevention. Thus, it is cost-effective, as prevention is better than cure in many cases (Babalola, Noel & White, 2017).

The treatment or therapy designed by the Bio-psychosocial theory of healthcare is tailor-made in order to suit a patient's physiological, psychological, and social needs and wants (Lewis, 2007). Unlike the biomedical theory that does not take the person's mind and

emotions as well as social effects into consideration, this approach is used on an individual level.

3.1.6 Disadvantages of the Bio-psychosocial Theory

The Bio-psychosocial theory assumes that all mental illnesses are, in fact, biopsychosocial. Critics feel that assuming every mental disorder to be biopsychosocial actually increases the stigma that is attached to these disorders, instead of reducing it (Smith, Fortin, Dwamena & Frankel, 2013). Assuming that a physical injury, or effect of society results in every mental illness is not practical, and if assumed thus, can also lead to confused treatment which may have grave consequences (Smith, Weihs, Alkozei, Killgore & Lane, 2018). Some mental disorders can be explained with the Bio-psychosocial theory; but it is wrongly assumed that the model is applicable to every disease (Shakespeare, Watson & Alghaib, 2017).

Some critics feel that incorrect behavior (such as anti-social behavior, for instance) cannot be treated as a medical condition, as very rarely do biological factors have a role in inducing it. Critics feel that assuming such behavior to be a disease reduces the credibility of the field of psychiatry, as it seems irrational to classify schizophrenia (a real disease) on the same lines as anti-social behavior (Benning, 2015).

According to some critics, another disadvantage of this model is that despite intensive efforts, it is very difficult to teach this theory to psychiatry students in an academic setting. Not all students are convinced by the three-fold approach of the theory, and are not convinced about its credibility or usefulness. Critics feel that the vagueness of the theory, and giving equal importance to all three factors in every situation, can discourage prospective psychiatry students from the very beginning, thus compromising on the number of students who wish to become psychiatrists (Suls & Rothman, 2004).

One more disadvantage of the theory as pointed out by critics is that, for a new user of this theory, it can be confusing and misleading to use it correctly and appropriately (Smith, Fortin, Dwamena & Frankel, 2013). The theory vaguely tends to suggest that biology and psychology are two separate fields in medicine. This leads to misunderstandings on the part

of a new user, who may not understand what symptom of a patient is to be categorized in which factor.

According to Worden, (2018), the Bio-psychosocial theory takes into consideration the effects of society on an individual, including his religious beliefs, primary and secondary relationships, work history, past incidents, etc. However, it can get very impractical to take so many social factors into consideration when trying to analyze a patient's problem. For experts, it can also be difficult to decide which social factors should be considered along with the psychological and biological factors. Hence, critics feel that treatment can get delayed or confused because of the consideration of so many things (Blascovich, Mendes, Tomaka, Salomon & Seery, 2003).

As we mentioned before, like every theory, the Bio-psychosocial theory too has its share of advantages and disadvantages. Whatever may be the reception of this theory today, we can conclude that the Bio-psychosocial theory to health and healthcare is very beneficial in several situations, and not so useful in others.

3.2. Criticisms of the BPS

Criticisms have been levelled at the BPS theory with suggestions that it is both time-consuming and expensive to apply (Gatchel & Turk, 2008). Time and cost are particularly pressing issues in resource-poor settings, where few healthcare professionals are available to attend to the large numbers of people experiencing mental health difficulties. It is claimed that the holistic nature of the BPS theory makes it a luxury many healthcare systems in low- and middle-income countries cannot afford. The BPS approach requires that more information be gathered during the assessment procedure about an individual's socioeconomic status, culture, religion, as well as psychological factors that might affect the individual's condition (Blascovich, Mendes, Tomaka, Salomon & Seery, 2003). There are often insufficient training opportunities or financial resources available to support the existence of multidisciplinary teams consisting of psychiatrists, clinical psychologists, mental health nurses, and social welfare workers to allow for a full consideration of the biological, psychological, and social factors involved in the mental health difficulties, with responsibility

instead often falling to physicians whose expertise may be limited to patient's biological complaints (Smith, Fortin, Dwamena & Frankel, 2013).

More recently, scepticism has sprung among mental health professionals surrounding the influence of the BPS theory in clinical practice. Scholar-practitioners have accused the theory's circular nature for failing to provide straightforward guidelines for clinical treatments or rules for prioritization in clinical practice. Some contend that a lack of clarity regarding whether biological, psychological, or social factors should be prioritized, have resulted in eclecticism in clinical practice and this "eclectic freedom borders on anarchy." Although clinicians may find the approach to be a useful heuristic and helpful for understanding clinical phenomena, its relevance for guiding clinical practice and alleviating distress remains ambiguous.

There is also the lack of scientific evidence to support the approach; McLaren described the model as a myth as it has no theory backing it up. Ghaemi (2015) opined that it is wrong to view the BPS theory as a concept and scientific fact. It is important to have empirical evidence of the effectiveness of the approach before regarding it as superior to other models before and after it. Critical voices posit the lack of implementation of the BPS theory as being due to an unwillingness to change among those who have power and influence in the mental health system. Whether due to shortcomings in the model or an unwillingness to change paradigms, the continuous commitment towards the biomedical paradigm within clinical practice is evidenced by the fact that the psychological and social factors are: "Often relegated to the role of triggers of an underlying genetic time bomb"; a diagnosis is considered most accurate if symptoms can be linked to physical anomalies and the effectiveness of psychosocial interventions is often measured in terms of medication adherence (Blascovich, Mendes, Tomaka, Salomon & Seery, 2003).

Furthermore, medical students in the US receive very limited amount of classes in psychosocial subjects compared to biomedical-oriented courses. This hierarchical dichotomization between the biological factors and the psychosocial ones, have led some to argue the BPS model serves to mask the biomedical model, and is in fact a "bio-bio-bio model" (Besemann et al., 2018). The mismatch between the "conceptual *status quo*" and

mental health care *praxis* has led to concerns being raised as to whether the BPS approach is a fully integrative framework, or whether it merely brings attention to three coexisting factors affecting health (Blascovich, Mendes, Tomaka, Salomon & Seery, 2003).

The lack of BPS integration in practice has also been noted in health psychology; empirical and theoretical integrations of the BPS domains remain slim despite the conceptual endorsement of the BPS theory. In addition, individualized and “intrapsychic” approaches to particular forms of distress (such as somatization) have been argued to reflect merely a Western cultural orientation. An additional criticism made by Sulmasy (2002) highlighted concerns that the BPS theory neglects the relational aspect a person has with transcendental factors, and calls for a “biopsychosocial-spiritual model” to truly account for the whole person. The influence that the BPS theory has had on understanding potential determinants.

3.3 The Afrocentric perspective

This study will also use the Afrocentric perspective as espoused by Molefi Kete Asante in order to understand challenging behaviour as will be explained by the teachers and parents of persons with intellectual disabilities from the African cultural point of view. This will allow the researcher to wholly understand a phenomenon in an African setting (Asante, 2017; Mkhabela, 2005). The Afrocentric perspective holds the notion of holism whereby a phenomenon has to be studied and understood in its entirety and not in fractions, more especially when it comes to studying African realities (Mazama, 2003). Therefore, in studying African culture and behaviour, it requires researchers to place African ideals, values, and philosophies at the centre of an analysis (Alkebulan, 2007). This will help the researcher to understand the selected mental health conditions from the perspective of the participants themselves, without any undue influence of the non-African approaches and practices. This endorses the assertion by the Afrocentric approach that Africans themselves, including their experiences should be at the centre of analysis, thereby removing Europe from the centre of the African reality (Asante, 1998; Mazama, 2003). The Afrocentric approach anchors itself on cultural and social realities that emphasise familiarity with history, language, philosophy and myths of Africans in their

own context (Mkhabela, 2005). The need for the use of this framework is also supported by the fact that the existing explanatory models of challenging behaviour are largely founded on Eurocentric culture, thus may be limited in other contexts. It therefore becomes imperative that a research effort into this area of research adopts a new lens which is informed by the local people's culture and traditions. It is on this basis that the current study will locate itself within the Afrocentric theoretical framework.

3.3.1 Conceptualizing the Afrocentric perspective

From the late 1980s to the mid-1990s many definitions of Afrocentricity were proffered by Africanists. The first definition was by Molefi Asante who defined Afrocentricity [African-centered] as the placing of African ideals at the centre of any analysis that involves African culture and behaviour (Asante, 1998). Secondly, the African centred perspective as an approach that rests on the premise that it is valid to position Africa as a geographical and cultural starting base in the study of peoples of African descent was defined by Tshehloane Keto (Keto, 1989). The third definition was by Wade Nobles who defined Afrocentric, Africentric, or African-centred as being interchangeable terms representing the concept which categorizes a quality of thought and practice which is rooted in the cultural image and interest of African people and which represents and reflects the life experiences, history and traditions of people as the centre of analysis (Nobles, cited in Jones 1990). The fourth definition was by Maulana Karenga who defined Afrocentricity as a quality of thought and practice rooted in the cultural image and human interest of African people and their descendants (Keto, 1989). Finally, Lathardus Goggins II defined African-centred as being able to construct and use frames of reference, cultural filters and behaviours that are consistent with the philosophies and heritage of African cultures in order to advance the interest of people of African descent (Pellerin, 2012).

The African perspective emphasizes the interconnectedness and interdependency of phenomena, including assumptions about human behaviour (Nobles, 2006). From this paradigm, all modalities of human behaviour are viewed as one, and there is no distinction between the spiritual and material, substance and form (Kambon & Bowen-Reid, 2010). Accordingly, all natural phenomena are functionally connected.

Schiele (1990) argues that because of its collective, spiritual or metaphysical, affective, and humanistic character, the Afrocentric perspective offers a more complete representation of human behaviour. Rational, objective, and material/object models, as espoused by the Eurocentric paradigm, fails to consider the humanism of people and the circumstances that preclude the use of rationality (Schiele, 1990). The tenets of the Afrocentric perspective reflect its collective, nonmaterial or spiritual, and affective character (Nobles, 2006).

The Afrocentric perspective conceives individual identity as collective and rejects the idea that the individual can be understood separate from others (Nobles, 2006). Mbiti (1970) puts it succinctly thus: "I am because we are and because we are, therefore I am" (p.141) to capture the essence of this collective identity. Because of this, Afrocentric paradigm gives pre-eminence to the group in that the welfare of the group takes precedence over the welfare of the individual. The Afrocentric paradigm places considerable emphasis on a collective conceptualization of human beings and on collective survival (Schiele, 1990).

The Afrocentric perspective recognises the spiritual or nonmaterial aspect of human beings. Accordingly, the mind, body, and soul are believed to be interdependent and interrelated phenomena (Schiele, 1990). Furthermore, the Afrocentric paradigm views much of human behaviour as deriving from feeling, rather than reasoning (Kambon & Bowen-Reid, 2010). This implies that, from an Afrocentric perspective, humans are influenced by a multitude of positive and negative life experiences resulting from social interaction. According to Nobles (2006), emotions elicited by these experiences can have an effect on the decisions, actions, and moods of people which sometimes obviates the exercise of rationality. This perspective of human behaviour refutes the assumption that human beings are invariably rational, mechanistic, and objective.

3.3.2 The theoretical principles of the Afrocentric perspective

The Afrocentric perspective locates research from an African viewpoint and creates Africa's own intellectual perspective (Mkhabela, 2005). Vaughn et al., (2009) argue that concepts of health and healing are rooted in culture. There is evidence that cultural practices affect an individual's behaviour as it relates to promoting, maintaining, and restoring health (Halbert et al., 2007). The Afrocentric perspective is appropriate for the

study in that there is a need for the conceptual paradigm that reflects the cultural background and reality of the African people. Afrocentric researchers discard positivist and nomothetic approaches to “reality” (Reviere, 2001). Positivist approach is exchanged for subjectivity and phenomenology as key concepts for understanding epistemology. The Afrocentric perspective seeks to place African ideals at the centre of any analysis that involves African culture and behaviour (Mazama, 2003). The Afrocentric idea rests on the assertion of the primacy of the African experience for African people (Kershaw, 1992). According to Asante (1991) puts it briefly thus: “...a frame of reference wherein phenomena are viewed from the perspective of the African person...It centres on placing people of African origin in control of their lives and attitudes about the world. As an intellectual theory, Afrocentricity is the study of the ideas and events from the standpoint of Africans as the key players rather than victims. This theory becomes, by virtue of an authentic relationship to the centrality of our reality a fundamentally empirical project...it is Africa asserting itself intellectually and psychologically, breaking the bonds of Western domination in the mind as an analogue for breaking those bonds in every other field” (p.172).

Karenga (1988) concurs with Asante and cogently defined Afrocentricity as “essentially a quality perspective or approach rooted in the cultural image and human interest of African people” (p.404). This paradigm espouses a commitment to African values, morals, and beliefs, which leads to a positive self-persona and positive ethnic association. Looking at the study with an Afrocentric lens will help in incorporating new strategies that are harmonious with the particular cultural styles, experiences, traditions, and interpretations of the African people, which can lead to more effective human services practice. Afrocentrism promotes an alternative social science paradigm more reflective of the cultural and political reality of the African people. It is, therefore, vitally critical to use a perspective that is grounded on traditional African philosophical assumptions.

The Afrocentric paradigm espouses the cosmology, aesthetics, axiology, and epistemology that characterize African culture. According to Mazama (2003), the Afrocentric research methodology (which is informed and derived from the Afrocentric paradigm) should be premised upon the following characteristics:

- A people's worldview determines what constitutes a problem for them and how they solve problems. As a result, Afrocentric scholarship must reflect the ontology, cosmology, axiology, and aesthetics of African people.
- The essence of life and therefore of human beings is spiritual. Therefore, Afrocentric methods as well as Afrocentrically generated knowledge must reflect the primacy of the spiritual, the relationship between the physical and the spiritual, as well as the interconnectedness of all things. The metaphysical concepts are also very important to Afrocentric subjectivity.

Afrocentricity constitutes a systematic approach to African phenomena where culture is emphasized as essential for the collective liberation of African people. Pellerin (2012) argues that it is imperative that Afrocentric methodologies are generated for and applied to the construction of research projects as well as the interpretation of research of African people. This is so mainly because a methodology not only generates new orientations toward interpreting data but ultimately employs research that is fruitful and liberating for African people. This involves placing African people as self-willed agents instead of objects of investigations.

Afrocentricity emerges as a methodology that consciously operates within the African ways of knowing and existence and results in the implementation of principles, methods, concepts, and ideas that are derived from African cultural experiences (Mazama, 2003). Afrocentricity constitutes the development of research whereby Africa is culturally asserted. The prioritization of African people's customs, beliefs, motifs, values, and conceptualizations is the rubric by which the application of an Afrocentric methodology operates. According to Pellerin (2012), Afrocentric methodologies must operate as valid and reliable research aimed towards the freeing of African people's thoughts and realities. Thus, Afrocentricity is the social science inquiry basis of African cultural phenomenon in practice. Pellerin (2012) maintains that collecting data for analysis and interpretation within an Afrocentric methodological context requires an Afrocentric orientation and interpretative framework.

According to Pellerin (2012), observations of African life entail a two-fold approach where the researcher witnesses a phenomenon and at the same time seeks clarity on that

phenomenon from the African people involved in that phenomenon. In the recording of explanations and observations, African voices must come through. Pellerin (2012) puts it briefly thus: “any deviation from what is African constitutes a shift in the interpretative framework and a shift in the understanding of African culture, life and experiences; thus directly results in flawed research observations and thus becomes tainted research that cannot be used to assess African phenomena”. The Afrocentric paradigm requires researchers to not simply describe a phenomenon, but to provide culturally infused descriptions and explanations of an African phenomenon. Reliability of an Afrocentric research project is achieved when the analysis of the data truthfully reflects the conditions of African people’s reality, and can be seen in the day- to-day lives of the population involved in the study (Mazama, 2003). Pellerin (2012) warns that analysis of an Afrocentric social science research project should also depend heavily on the researcher’s ability to produce sophisticated data analysis rooted in the insights gained from not only observing but also comprehending African reality from an African perspective. As a result, the conceptual procedures used in Afrocentric data analysis must align with Afrocentric conceptual frameworks in order to assure accurate examinations and interpretations of observations.

3.3. Utilising both the Bio-psychosocial and Afrocentric perspectives as a theoretical lens

The Bio-psychosocial theory emphasises the interplay of biological (genetic predisposition), psychological or behavioural (lifestyles, explanatory styles, health beliefs), and social factors (family relationships, socioeconomic status, social support) in the explanation of pathogenesis and health aetiology (Hatala, 2012). This theory explains that all the three domains play an equal part in the manifestation of all the health situations, and that none of them may be used in isolation to explain any patient or pathology with the exclusion of the other two (Ghaemi, 2015), in this instance challenging behaviours in persons with intellectual disabilities. However, one of the major criticisms of the Biopsychosocial Theory is that it does not account for cultural or normative factors (Rosenstock, 1974). Within the context of this study, however, the shortcomings of the Biopsychosocial Theory were minimised by using a blend of the Biopsychosocial Theory

and Afrocentric perspective as the conceptual framework. For this purpose, a combination of the Biopsychosocial Theory and Afrocentric viewpoint becomes important in an attempt to understand and develop a culturally informed explanatory model for challenging behaviour in persons with intellectual disabilities.

The primary reason for using a blended model as the conceptual framework in this qualitative study is that the Afrocentric viewpoint allows for a culturally-based relevance, dimension that is lacking in the Bio-psychosocial theory. The Afrocentric viewpoint will bring the cultural component to the framework.

3.4 Conclusion

In conclusion, the BPS theory has contributed to an eschewing of deeply ingrained features of the Western/European “folk model” such as the mind-body split and made an important conceptual contribution for understanding mental health difficulties in a more all-encompassing fashion. This study will highlight a need to extend the BPS approach to include a specific acknowledgement of the central role that cultural beliefs and practices can play in understanding mental health difficulties. This will help facilitate a focus on particular idioms of distress that are highly relevant for developing interventions for mental health difficulties in different sociocultural contexts. In short, for the BPS approach to be a truly “holistic” model it will need to be sensitive to the diversity of beliefs and practices espoused by people across the globe. A greater focus on cultural factors could also potentially address a criticism that has been made to the BPS model, i.e., a lack of specific guidance relating to how support can be operationalized and offered to clients. Increased understanding about pertinent cultural factors could inform understanding about the people, processes, spaces, and places in which acceptable forms of support can be provided.

Therefore, combining the Bio-psychosocial and the Afrocentric perspective as a framework for the study will help to bring together the two critical important determinants of human behaviour. The basic components of the biopsychosocial are derived from a well-established body of psychological and behavioural theory. The Afrocentric perspective places the African experience at the centre. In the context of the present

study, the researcher will use both the Afrocentric and the bio-psychosocial theories as lenses to understand and explain challenging behaviour by teachers and parents. In other words, the researcher will mobilise both theoretical frameworks to understand challenging behaviour of persons with intellectual disability both from an Afrocentric perspective, and also from the bio-psychosocial view that takes into account the individual's bio-psycho-social and cultural experiences. The choice of the two theoretical lenses will thus accommodate the epistemological foundations that underpin the two perspectives.

The next chapter presents the methodology followed in conducting the study. The research design, data collection and analysis methods are outlined in the next chapter. The issues of quality as it pertains to this study are outlined, followed, lastly, by the presentation of ethical issues followed in conducting the study.

CHAPTER 4

METHODOLOGY

In this chapter, the methodology that was used in the study is presented. In the first part of the chapter, a brief overview of the two widely used research paradigms (namely, quantitative and qualitative research paradigms) including their philosophical assumptions, is presented. The qualitative research paradigm is critically discussed in more detail, also motivating why the researcher opted to use the qualitative research paradigm. The research design of choice for the study, namely the exploratory approach, is presented. The second part of the chapter will be a presentation of the specific methods such as sampling, data collection and data analysis. In the third part, issues of quality assurance, and how this was ensured in the present study are addressed. The fourth and final part of the chapter addresses ethical issues that guided the researcher.

4.1. Qualitative and quantitative research paradigms

The realm of scientific research has two distinctly dichotomous worldviews or methods of searching for the truth exist, namely, quantitative and qualitative approaches. What follows is a review of the literature on the quantitative research paradigm, including its philosophical foundations and basic assumptions, as well as its strengths and weaknesses as a vehicle through which scientific investigations and inquiries are made. In the second part of this section a similar review of the qualitative research paradigm will be done. In the third part, a motivation is given as to why the latter paradigm was chosen for the present study.

4.1.1. Quantitative research paradigm

Quantitative research paradigm is made up of methods that are mainly concerned about the quantification of data for the purpose of generating an understanding of the phenomena being studied. Scholars who operate in this paradigm view reality as something 'out there' to be observed (Choy, 2014). They also strongly believe in the existence of the empty perceptual space between the researcher and the researched. In this regard, there is an assumption that the world is structured by law like generalities that can be identified, predicted, manipulated or controlled to yield universal statements of

scientific theory (Robinson, 2014). Quantitative research is generally nomothetic, that is, its focus is on generalisation and working towards the development of universal statements or laws (Choy, 2014). Quantitative research methods are characterised by the collection of information which can be analysed numerically, the results of which are typically presented using statistics, tables and graphs (Choy, 2014). Among several strengths of quantitative research is the fact that larger sample sizes tend to be used for collecting data, so as to gather as representative picture as possible (Smith et al., 1995).

Typically a problem or question, composed of variables, is measured in a systemic way and data are analysed with statistical procedures. Some characteristic features of quantitative inquiry that guide data collection and analysis include focus on control to establish cause or permit prediction, the use of standardized measurements, and perform data analysis in a prescribed, standardised, linear fashion (Choy, 2014). Quantitative methods stress objectivity as opposed to conformability in research. Historically, many areas of academic research have utilized quantitative methods (Choy, 2014). The emphasis was on what was observable and accessible, with researchers concerning themselves primarily on those areas and questions that are amenable to the adherence of empirical methods of inquiry. Despite all of the above, it is worth noting that the major weakness of quantitative research is that it fails to appreciate the fact that while some study problem are topical, they cannot be well-understood through numerical representation.

4.1.2. Qualitative research paradigm

Qualitative research, on the other hand, is comprised of a collection of methods of inquiry which were borne out of a growing disenchantment with the limits of logical- empirical research methodologies (Osborne, 1994). Increasingly, questions began to emerge in some quarters of research about the focus of inquiry, as well as exploration of methodologies that emphasized discovery, description of meaning rather than prediction, control and measurement. Most researchers refer to this period as an era of growing crisis for the mainstream positivist research ideology as both the philosophies and methodologies used in research were been rethought. There was a notable growing recognition of the limitations of addressing many significant questions, particularly in the

realm of human experience, within the requirements of empirical methods. Qualitative research usually adopts a generally idiographic stance, that is, its focus is on contextual individuality and uniqueness (Smith et al., 1995). The foregoing observation implies that in order to understand a complex phenomenon, you must consider multiple “realities” experienced by the participants themselves (Smith & Osborn, 2007). The search for an objective reality, strongly emphasized by quantitative researchers, is abandoned in favour of the assumption that people construct their own personal worlds espoused by qualitative researchers (Smith & Osborn, 2007). Within the qualitative paradigm, natural environments or settings are favoured for discovering how participants construct their own meanings of events or situations as opposed to fixed experiments or quasi-experiments. The most common sources of qualitative data include interviews, observations, and documents (Choy, 2014). The goals of qualitative data analysis are to uncover emerging themes, patterns and understandings (Choy, 2014). Regardless of the imperfections of qualitative research, its strength lies in the ability to generate an enriched understanding of the phenomena being studied with the context of limited participants. Some of the observable weaknesses of qualitative research are derived from the potential bias of the researcher to influence his/her study conclusions.

4.1.3. Justification for the use of qualitative research in this study

The purpose of this study was to explore and analyse the notions, experiences, perceptions, and beliefs about challenging behaviour of a sample of teachers and parents of persons with intellectual disabilities. Based on their notions, causal explanations and beliefs about appropriate interventions, develop and articulate an explanatory model on challenging behaviour in persons with intellectual disabilities. According to Choy (2014), the only way for a researcher to really understand what another person experiences is to investigate the phenomenon as directly as possible. Qualitative research uses inductive form of reasoning, that is, it uses the *emic* perspective of inquiry Choy (2014). By *emic* it means that the meaning is derived from the participants’ perspective. Qualitative research uses words as the basis for analysing rather than numerical data (Choy, 2014). Qualitative research approach captures and discovers meaning once the researcher becomes immersed in the data in their quest to understand a particular phenomenon.

Since human experiences are difficult to quantify, qualitative research becomes the more effective method of investigation.

Choy (2014) argues that choosing a design involves assessing which paradigms best fit with your own assumptions and methodological preferences. Choy (2014) outlines three key concepts which provide the foundations for conducting qualitative research in the social sciences. A researcher's epistemological stance is the first fundamental component which needs to be clarified as this position has a direct impact on the specific approach taken (methodology) which in turn provides justification for specific techniques used to gather the data (method) (Langdrige, 2007). Epistemology has its roots in philosophy and is concerned with the 'theory of knowledge' (Thomas, 2009). When thinking epistemologically, scientists or researchers should attempt to answer questions such as, 'what is the nature of knowledge?' and 'how is knowledge produced' (Willig, 2013).

Mantzoukas (2004) argues that a researcher's epistemological stance is directly related to their ontological position and therefore this should also be clarified at the outset of the research process. Ontology is specifically concerned with the nature of the world (Willig, 2013). The purpose of this research was to understand and describe the notions of challenging behaviours in persons with intellectual disabilities by parents and teachers. This will involve exploring their thoughts, feelings, perceptions and reflections in order to gain insight into how they make sense of and understand their notions. I will argue that the most appropriate way to capture this is to gain detailed personal accounts and this research was therefore qualitative in nature.

4.2. Research design

Rooted in an interpretivist paradigm, this study utilised qualitative research methods (Nieuwenhuis, 2016b; Terre Blanche & Durrheim, 2011). The nature of the study required that the researcher engages with the participants closely, and on a personal level during the process of collecting the data. As recommended by Ponelis (2015), an exploratory approach was followed as a design for the research. As stated by Durrheim (2011), exploratory studies do preliminary investigations of relatively unknown areas of research. Given the lack of local research on the topic, the experiences of these parents and

teachers are relatively unknown and the exploratory design was therefore considered useful for the research.

This design was found most appropriate for the present study as it allows for research conducted to gain new insights, discover new ideas, and for increasing knowledge of the phenomenon.

In addition, the researcher will be guided by the principles of Afrocentricity as espoused by Mkabela, (2005) who asserted that any study that involves Africans should take into account the cultural background and reality of the African people. This is because the ideas and events will merge from the standpoint of Africans.

As articulated by Mkabela (2005), among other principles of Afrocentricity to be used as the analytical categories for this study includes an appreciation of the importance of all individuals in the research group; an understanding that research is part of a very complex (community) whole; an understanding of the interconnectedness of all things (including the spiritual) and a required long term perspective in dealing with research issues and that researchers must act in an appropriate and respectful way to maintain the harmony and balance of the group (community).

Hinduism, Islam, 1.5%, 0.6% other, 15.1% no religion, and 15.1% undetermined (Stats SA, 2001). The predominant languages spoken in Limpopo Province are Sepedi (52.9%), Xitsonga (17%) and Tshivenda (16.7%) (Stats SA, 2015). Although English is the mother tongue of only 8.2% of the population of South Africa, it is the language most widely understood, and the second language of the majority of South Africans (Stats SA, 2015).

4.3.2 Population

The target population is not only a practical boundary that aids the process of sampling, but it also provide an important theoretical role in the analysis and interpretation process by specifying what a sample is, and thus defining who or what the study is about. The level of generality to which a study's findings is relevant and logically inferable is the sample universe, thus the more clearly and explicitly a sample universe is described, the more valid and transparent any generalisation can be (Robinson, 2014).

The target population of the study live in Ga-Dikgale and Ga-Molepo villages that are located in the Capricorn district, Limpopo Province. These villages were chosen because they have schools for children with ID. There are children who have been formally diagnosed with ID in this area. The villages were chosen instead of suburbs because in South Africa it is mostly in villages that disability has a severe impact on those affected (Education White Paper 6, 2001).

4.3.3 Sampling

The participants for the study were recruited using a purposive sampling technique. Purposive sampling is when a researcher chooses specific people within the population to use for a particular study or research project (Choy, 2014). The rationale for using purposive sampling strategy is that the researcher assumes that, based on his/her theoretical understanding of the topic being studied, that certain categories of individuals may have a unique, different or important perspective on the phenomenon in question and their inclusion in the sample should be ensured. The participants in purposive sampling are chosen based on a particular characteristic and in this case the parents and teachers of persons with intellectual disabilities.

In deciding on the sampling, a four-point approach suggested by Robinson (2014) was followed, namely:

- To establish a sample universe, specifically by way of a set of inclusion and/or exclusion criteria. In the case of the present study, this was achieved by specifically selecting available biological parents and teachers of persons with intellectual disabilities. Parents who shown signs of being under the due influence of substances were excluded.
- To choose a sample size or sample range, by taking into account what is ideal and what is practical. In the context of this study, this was realised by drawing selected participants from the two special schools that are near the researcher's host institution.
- To select a purposive sampling strategy to specify categories of person to be included in the sample. In this case, this study has limited itself to parents and teachers of persons with intellectual disabilities.
- To recruit participants from the target population. In this study, recruitment of targeted participants was done until a point of saturation in terms of data collection.

The size of a sample used for qualitative research project is influenced by both theoretical and practical considerations (Robinson, 2014). Interviews done in this study, typically aims to seek a sample size that is sufficiently small for individual cases to have a locatable voice within the study, and for an intensive analysis of each case to be conducted.

For these reasons, participants are parents and teachers of persons with intellectual disabilities portraying challenging behaviours, and residing within the Capricorn District of the Limpopo Province. Therefore, in the present study, the researcher conveniently drew participants from *Bana ba Thari* and *Benedict and Hope* special schools as they are most accessible. These two schools cater for persons with intellectual disabilities, and are based in the Capricorn District of Limpopo Province. Parents and teachers of persons with intellectual disabilities were be purposefully sampled from the two schools and interviewed. Though an initial sample of 20 participants (10 parents and 10 teachers) was envisaged, enlistment of participants however continued until a point of saturation as recommended by Fusch & Ness, (2015). In this regard, the researcher ended up with 23 participants (teachers = 11; parents = 12). With regard to the parents, the researcher was

biased in the selection of participants in favour of mothers, unless mothers were showing signs of intellectual disability were replaced by the fathers and also accepted single parents who are fathers. This meant to take into account research evidence indicating that mothers are commonly the ones taking care of children with intellectual disabilities (Dabrowska & Pisula, 2010).

Deliberate and critical reflection considering the research problem, the life-world position of the participants, the quality of the data, and the value of emergent findings with regard to the research goals determined the adequacy of the sample size of twenty-three (23) participants (Robinson, 2014). To delineate a sample, a set of inclusion and exclusion criteria, or a combination of both, must be specified for the study (Patton cited in Robinson, 2014). Inclusion criteria must specify an attribute or attributes that case must possess to qualify for the study, while exclusion criteria must stipulate attributes that disqualify a case from the study. Together, these criteria drew a boundary around the target population. The more inclusion and exclusion criteria that are used to define a target population, and the more specific these criteria are, the more homogeneous the target population becomes. As Robinson (2014) puts it, the extent of target population homogeneity that a research study aims for is influenced by both theoretical and practical factors.

4.3.4 Inclusion and exclusion criteria

The inclusion criteria for participation in the study were as follows:

- The biological parents of the person with ID taking care of the child/children on a day-to-day basis and had to have been the consistent primary caregivers of the child for at least a year
- Willing teachers of persons with intellectual disabilities.
- Be able to communicate in at least one of the following languages, Sepedi, Xitsonga, Tshivenda, or English.

Criteria for exclusion from participation in the study were as follows:

- Those showing signs of intoxication during the time of the interview had their appointments cancelled also. This is because the researcher felt that such parents could potentially become difficult to manage because of their intoxication. They may also misunderstand the interview question as a result of their lack of concentration caused by the intoxication. Intoxicated people can also act reckless and violent.
- Individuals who fulfil the inclusion criteria but not wishing to take part.
- Individuals who fulfil the inclusion criteria but who found it very difficult to speak.

The bias towards Sepedi, Xitsonga, and Tshivenda speakers as the categories of persons to be included in the sample was largely for practical reasons in that they are the most commonly spoken languages by black people in the Province of Limpopo.

4.4. Data collection

Interviewing the teachers in their classrooms after hours and parents in their homes was the most appropriate data collecting instrument considering the nature of the study. This is because interviewing participants in their homes as compared to other means of data collecting methods like using questionnaires or telephonic interviews, help researchers make sense of the participants' feelings, experiences, social situations or the phenomena in their natural settings (Kelly, 2011). The face-to-face interviews also gave the researcher a better chance to establish rapport with the participants, something that Kelly (2011) and Nieuwenhuis (2016) say is more possible through live interviews than observations and questionnaires.

Data collection can also create a free and non-threatening environment for both the researcher and the participant, especially if the researcher is well trained in conducting effective interviews by for instance being able to become a natural part of the context in which the research phenomenon appears (Kelly, 2011). One way of ensuring that one becomes a natural part of the context being researched is by showing natural care and engaging with the participant in an open and emphatic manner (Kelly, 2011). Knowing that ID is often viewed as a very sensitive topic in South Africa, particularly in villages (Laas, 2012), all these factors had to be considered in choosing a data collecting method.

Participants were fully enabled to open up about their experiences during the interviews. The average duration of the interviews was forty-five minutes, with the longest interview having gone just over an hour and the shortest one being thirty minutes. The interviews were mainly open-ended interviews (see the interview guide under appendix 1). Nieuwenhuis (2016) describes an open-ended interview as an interview that often takes the form of a conversation with the intention that the researcher explores with the participant his or her views, ideas, beliefs and attitudes about certain events or phenomena.

Semi-structured, in-depth, one-on-one interviews are the most suitable data collection method to achieve this purpose (Smith, 2012). The method is particularly useful for in-depth idiographic studies exploring how participants are making sense of their experiences (Shinebourne, 2011). Semi-structured interviews allow the researcher and the participants to engage in a conversation. This method also gives enough space and flexibility for original and unexpected materials to arise, which the researcher may inquire in more detail with probing questions (Smith, 2012).

The interviews were semi-structured and “semi-formal” in nature. Nieuwenhuis (2016) states that semi-structured interviews seldom spans a long time period and usually requires the participant to answer a set of predetermined questions. It does allow for the probing and clarification of answers he further states. By “semi-formal”, the researcher means that the interviews were between formal and informal by the manner they took place. That is, as much as there was a predetermined main question and there were follow up questions, set interview dates, times and locations (which made the interviews quite formal), the actual interviews were relaxed chats and conversations between the researcher and the participants where the researcher allowed participants to approach the whole process in their own preference and did so while relaxed in the comfort of their own bedrooms/couches and teacher’s classrooms (and this made the interviews to be quite informal).

- Following the consent process, the researcher went back to the list of all the parents and teachers who gave their consent and started to call the parents to

make interview appointments with them. The teachers and parents chose specific dates and times that suited their schedules. Where both parents were available and both decided to be part of the study, they were interviewed together, and that counted as one interview.

- One parent preferred not to use their home for the interview. They were transported to their child's classroom at the special school for the interview after signing an indemnity form from the school for being transported. The school is clean, safe (with twenty-four hour security), well-resourced and well looked after. It was therefore conducive to such an activity.
- The interview schedule was written in English and Sepedi. The researcher read and explained it to each participant in their language before they were given the chance to respond.
- A tape recorder was used to record the interviews. The participants were made aware of this during the initial visit to their home (see the Appendix 3 for the interview schedule).

4.5. Data analysis

The study made use of thematic content analysis (TCA) to analyse the data. According to Vaismoradi, et al. (2013), thematic content analysis belongs to the continuum of qualitative data analysis wherein a low level of interpretation is anticipated. Thematic content analysis can take the form and shape of realist or constructivist paradigm, with potentially radical outcomes for the findings. Emerging from this, the present study best fits into constructivist paradigm. This is because the epistemic location of this study subscribes to the belief that truth is socially constructed. As an analysis approach that is based on interpretive philosophy, which is aimed at examining meaningful and symbolic content of qualitative data it assumes the form of the generation and presentation of data into themes and sub-themes (Terre-Blanche, Kelly & Durrheim, 2011). This type of analysis tries to establish how participants derive meaning from a specific phenomenon by analysing their perceptions, attitudes, understanding, knowledge, values, feelings and experiences in an attempt to approximate their construction of the phenomenon (Nieuwenhuis, 2016).

'Thematic content analysis', a technique that researchers use to develop a theory and themes by studying data (Nieuwenhuis, 2016a), was used as the technique through which the data were analysed. It relies, as Nieuwenhuis (2016) explains, on inductive reasoning where themes and sub-themes emerge from the collected data through repeated examination and comparison, so that the results can be coded and categorized according to their similarities and differences.

The focus of this study was to understand and explain notions of challenging behaviour from parents and teachers of persons with ID to develop and articulate an explanatory model of challenging behaviour in persons with intellectual disabilities. The study probed their personal responses to these experiences and/or understanding, causal experiences and the coping strategies of challenging behaviour that they employ. Following the technique of thematic content analysis, the researcher worked through the data to identify categories with codes. After feedback the categories were revised until the final themes and categories emerged. Quotes from participants' responses are cited in the report as part of the results.

Thematic content analysis is one of the most common forms of analysis in qualitative research. It emphasizes pinpointing, examining, and recording patterns (or "themes") within data. Themes are patterns across data sets that are important to the description of a phenomenon and are associated to a specific research question. Thematic analysis is best thought of as an umbrella term for a variety of different approaches, rather than a singular method. Different versions of thematic analysis are underpinned by different philosophical and conceptual assumptions and are divergent in terms of procedure.

4.7. Rationale for selecting TCA

Braun and Clarke (2006) argued that thematic content analysis should be a foundational method for qualitative analysis, as it provides core skills for conducting many other forms of qualitative analysis. Thematic content analysis is a type of qualitative analysis used to analyse classifications and present themes (patterns) that relate to the data. It illustrates

the data in great detail and deals with diverse subjects via interpretations (Boyatzis, 1998).

Thematic content analysis is considered the most appropriate for any study that seeks to discover using interpretations. It provides a systematic element to data analysis. It allows the researcher to associate an analysis of the frequency of a theme with one of the whole content. This will confer accuracy and intricacy and enhance the research's whole meaning. Qualitative research requires understanding and collecting diverse aspects and data. Thematic content analysis gives an opportunity to understand the potential of any issue more widely (Marks and Yardley 2004).

Guest, MacQueen, & Namey, (2008) said thematic moves beyond counting explicit words or phrases and focuses on identifying and describing both implicit and explicit ideas. Codes developed for ideas or themes are then applied or linked to raw data as summary markers for later analysis, which may include comparing the relative frequencies of themes or topics within a data set, looking for code co-occurrence, or graphically displaying code relationships.

Thematic content analysis allows the researcher to determine precisely the relationships between concepts and compare them with the replicated data. By using, thematic content analysis there is the possibility to link the various concepts and opinions of the learners and compare these with the data that has been gathered in different situation at different times during the project. All possibilities for interpretation are possible.

Thematic content analysis is a qualitative research method that can be widely used across a range of epistemologies and research questions. It is a method for identifying, analysing, organising, describing, and reporting themes found within a data set Braun & Clarke, 2006. Braun and Clarke (2006) argued that thematic content analysis should be a foundational method for qualitative analysis, as it provides core skills for conducting many other forms of qualitative analysis.

Through its theoretical freedom, thematic content analysis provides a highly flexible approach that can be modified for the needs of many studies, providing a rich and detailed, yet complex account of data (Braun & Clarke, 2006; King, 2004). As thematic

content analysis does not require the detailed theoretical and technological knowledge of other qualitative approaches, it offers a more accessible form of analysis, particularly for those early in their research career (Braun & Clarke, 2006). Researchers who are relatively unfamiliar with qualitative methods may find that thematic content analysis is easily grasped and can be relatively quick to learn, as there are few prescriptions and procedures (Braun & Clarke, 2006; King, 2004). Braun and Clarke (2004) and King (2004) argued that thematic content analysis is a useful method for examining the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights. Thematic content analysis is also useful for summarising key features of a large data set, as it forces the researcher to take a well-structured approach to handling data, helping to produce a clear and organized final report (King, 2004).

Many authors have maintained that because thematic content analysis is a process used by many qualitative methods, it is not a separate method, rather something to be used to assist researchers in analysis (Boyatzis, 1998; Holloway & Todres, 2003; Ryan & Bernard, 2000). Others have also claimed that thematic content analysis should be considered a method in its own right (Braun & Clarke, 2006; King, 2004; Leininger, 1992; Thorne, 2000). Thematic content analysis is also argued to be a qualitative research method that can be widely used across a range of epistemologies and research questions. It is a method for identifying, analysing, organising, describing, and reporting themes found within a data set (Braun & Clarke, 2006).

4.8 Limitations of TCA

Criticisms of TCA is alluded that it has been poorly branded, yet widely used in qualitative research (Braun & Clarke, 2006), and has been rarely appreciated in the same way as grounded theory, ethnography, or phenomenology.

A rigorous thematic content analysis can produce trustworthy and insightful findings (Braun & Clarke, 2006); however, there is no clear agreement about how researchers can rigorously apply the method. Although thematic content analysis has been described (Nowell, Norris, White & Moules 2017), guides on conducting thematic analysis have primarily focused on conducting research with an applied focus (Namey et al., 2008) or described inductive versus deductive coding (Fereday & Muir-Cochrane, 2006). While

much has been written about grounded theory, ethnography, and phenomenology, this trend has not yet reached thematic content analysis. There is insufficient literature that outlines the pragmatic process for conducting trustworthy thematic content analysis.

The disadvantages of thematic content analysis become more apparent when considered in relation to other qualitative research methods. The lack of substantial literature on thematic content analysis—compared to that of grounded theory, ethnography, and phenomenology, for example—may cause novice researchers to feel unsure of how to conduct a rigorous thematic content analysis. A simple thematic content analysis is disadvantaged when compared to other methods, as it does not allow researcher to make claims about language use (Braun & Clarke, 2006). While thematic content analysis is flexible, this flexibility can lead to inconsistency and a lack of coherence when developing themes derived from the research data (Holloway & Todres, 2003). Consistency and cohesion can be promoted by applying and making explicit an epistemological position that can coherently underpin the study's empirical claims (Holloway & Todres, 2003).

4.9 Stages of TCA analysis

In this study, the researcher specifically analysed the data in accordance with the following steps as outlined by Terre Blanche, Durrheim and Painter (2009). The analysis started first with the transcription of the digital record of the interviews followed by the analysis.

4.9.1 Phase 1: Becoming familiar with the data

The initial phase in thematic content analysis is for the researcher to familiarise herself with the data. Prior to reading the interview transcripts, researchers may create a "start list" of potential codes. These start codes should be included in a reflexivity journal with a description of representations of each code and where the code is established. Analysing data in an active way assisted the researcher in the present study in searching for meanings and patterns in the data set. At this stage, it was tempting to skip over the data; however, this assisted the researcher in identifying possible themes and patterns. Reading and re-reading the material was maintained until the researcher was comfortable with data and this was crucial to the initial phase of analysis. While becoming familiar with

the material, note-taking was a crucial part of this step in order begin developing potential codes.

After completing data collection through interviews, the researcher began transcribing the data into written form. Transcription of the data was imperative to the dependability of analysis. Criteria for transcription of data was established before the transcription phase was initiated to ensure that dependability is high. Inconsistencies in transcription can produce biases in data analysis that will be difficult to identify later in the analysis process. The protocol for transcription should explicitly state criteria of transcription. Inserting comments like "*voice lowered*" will signal a change in the speech. During this stage, it was especially important to draw upon non-verbal utterances and verbal discussions to lead to a richer understanding of the meaning of data. A general guideline to follow when transcribing included a ratio of 15 minutes of transcription for every 5 minutes of dialog.

After this stage, the researcher felt familiar with the content of the data and was able to identify overt patterns or repeating issues in one or more interviews. These patterns were recorded in a reflexivity journal where they were used when coding and checking for accuracy. Following the completion of the transcription process the researcher's most important task began to gain control over the data. At this point, it was important to mark data that addresses the research objectives. This was the beginning of the coding process.

4.9.2 Phase 2: Generating initial codes

The second step in thematic content analysis is generating an initial list of items from the data set that have a reoccurring pattern. This systematic way of organising, and gaining meaningful parts of data as it relates to the research question is called coding. The coding process evolves through an inductive analysis and is not considered to be a linear process, but a cyclical process in which codes emerge throughout the research process. This cyclical process involves going back and forth between phases of data analysis as needed until you are satisfied with the final themes. According to Bengtsson (2016), researchers conducting thematic content analysis should attempt to go beyond surface

meanings of the data to make sense of the data and tell an accurate story of what the data means.

The coding process was rarely completed the first time. Each time, the researcher should strive to refine codes by adding, subtracting, combining or splitting potential codes. Start codes were produced through terminology used by participants during the interview and can be used as a reference point of their experiences during the interview. Dependability increases when the researcher uses concrete codes that are based on dialogue and are descriptive in nature. These codes will facilitate the researcher's ability to locate pieces of data later in the process and identify why they included them. Initial coding sets the stage for detailed analysis later by allowing the researcher to reorganize the data according to the ideas that have been obtained throughout the process. Reflexivity journal entries for new codes serve as a reference point to the participant and their data section, reminding the researcher to understand why and where they will include these start codes in the final analysis. Throughout the coding process, full and equal attention was paid to each data item because helped in the identification of unnoticed repeated patterns. Coding for as many themes as possible and coding individual aspects of the data may seem irrelevant but can potentially be crucial later in the analysis process.

Coding also involves the process of data reduction and complication. Reduction of codes is initiated by assigning tags or labels to the data set based on the research question(s). During this stage, the researcher condensed large data sets into smaller units which assisted to permit further analysis of the data by creating useful categories. Coding aids in development, transformation and re-conceptualization of the data and helped to find more possibilities for analysis.

4.9.2.1 Data reduction: Coding can be thought of as a means of reduction of data or data simplification. Using simple but broad analytic codes it is possible to reduce the data to a more manageable feat. In this stage of data analysis the researcher focused on the identification of a more simple way of organising data. The researcher included a process of indexing the data texts which included field notes, interview transcripts and other

documents. Data at this stage was reduced to classes or categories in which the researcher was able to identify segments of the data that share a common category or code. Siedel and Kelle (1995) suggest three ways to aid with the process of data reduction and coding: (a) noticing relevant phenomena, (b) collecting examples of the phenomena, and (c) analysing phenomena to find similarities, differences, patterns and overlying structures. This aspect of data collection was important because during this stage the researcher was attaching codes to the data by allowing her to think about the data in different ways. Coding cannot be viewed as strictly data reduction, data complication can be used as a way to open up the data to examine further. The below section addresses the process of data complication and its significance to data analysis in qualitative analysis.

4.9.2.2 Data complication: The process of creating codes can be described as both data reduction and data complication. Data complication can be described as going beyond the data and asking questions about the data to generate frameworks and theories. The complication of data was in this study was used to expand on data to create new questions and interpretation of the data. At this stage the researcher made certain that the coding process does not lose more information than was gained. Tesch (1990) defines data complication as the process of reconceptualising the data giving new contexts for the data segments. Data complication served as a means of providing new contexts for the way data was viewed and analysed.

Coding is a process of breaking data up through analytical ways and in order to produce questions about the data, providing temporary answers about relationships within and among the data. Decontextualising and recontextualising of data help to reduce and expand the data in new ways with new theories (Bengtsson, 2016).

4.9.3 Phase 3: Searching for themes

Searching for themes and considering what works and what does not work within themes enables the researcher to begin the analysis of potential codes. In this phase, it was important to initiate examining how codes were combined to form over-reaching themes in the data. At this point, the researcher had a list of themes and began to focus on broader patterns in the data, combining coded data with proposed themes. The researcher also

considered how relationships are formed between codes and themes and between different levels of existing themes. It would have also been helpful to have used visual models to sort codes into the potential themes.

Themes differ from codes in that themes are phrases or sentences that identifies what the data means, this is illustrated in the results chapter. Themes describe an outcome of coding for analytic reflection. Themes consist of ideas and descriptions within a culture that can be used to explain causal events, statements, and morals derived from the participants' stories (Braun & Clarke (2006). In subsequent phases, it was important to narrow down the potential themes to provide an overarching theme. Thematic content analysis allows for categories or themes to emerge from the data like the following: repeating ideas; indigenous terms, metaphors and analogies; shifts in topic; and similarities and differences of participants' linguistic expression. It was important at this point to address not only what is present in data, but also what was missing from the data. In the results chapter it was stated that the conclusion of this phase yield themes collected throughout the data process. It was crucial to avoid discarding themes even if they were initially insignificant as they might have remained important themes later in the analysis process.

4.9.4 Phase 4: Reviewing themes

This phase requires the researcher to search for data that supports or refutes the proposed theory. This allowed further expansion on and revision of themes as they develop. At this point, the researcher had a set of potential themes, as this phase is where the reworking of initial themes took place. Some existing themes may have collapsed into each other, other themes may have needed to be condensed into smaller units.

Specifically, this phase involves two levels of refining and reviewing themes. Connections between overlapping themes may serve as important sources of information and can alert researchers to the possibility of new patterns and issues in the data. Deviations from coded material can notify the researcher that a code may not actually exist. Both of these acknowledgements should be noted in the researcher's reflexivity journal, also including the absence of themes (Braun & Clarke, 2006). Codes served as a way to relate data to a

person's conception of that concept. At this point, the researcher should focus on interesting aspects of the codes and why they fitted together.

4.9.4.1 Level 1: Reviewing coded data extracts allows the researcher to identify if themes form coherent patterns. If this is the case, the researcher should move onto Level 2. If themes do not form clear patterns, consideration of the potentially problematic themes should be considered in addition to determining if data does not fit into the theme. If themes are problematic, it is important to rework the theme and during the process, identification of new themes may emerge. For example, it would be problematic when themes do not appear to work or a significant amount of overlap between themes exists. This can result in a weak or unconvincing analysis of the data. If this occurs, data may need to be recognized in order to create cohesive, mutually exclusive themes.

4.9.4.2 Level 2: Considering the validity of individual themes and how they connect to the data set is crucial to completing this stage. It is imperative to assess whether the potential thematic map accurately reflects the meanings in the data set in order to provide an accurate representation of participants' experiences. Once again, at this stage it was important to read and re-read the data to determine if current themes relate back to the data set. To assist the researcher in this process it is imperative to code any additional items within the themes that may have been missed earlier in the initial coding stage (Braun & Clarke, 2006). If the potential map works then the researcher should progress to the next phase of analysis. If the map does not work it was crucial to return to the data in order to continue to review and refine existing codes. Mismatches between data and analytic claims reduce the amount of support that can be provided by the data. This was avoided when the researcher was certain that her interpretations of the data and analytic analysis corresponded. The researcher repeated this process until she was satisfied with the thematic map. By the end of this phase, the researcher had an idea of what themes are and how they fit together so that they convey a story about the data set.

4.9.5 Phase 5: Defining and naming themes

Defining and refining existing themes that was be presented in the final analysis assisted the researcher in analysing the data within each theme. At this phase, identification of the

themes' essence related to how each specific theme affects the entire picture of the data. Analysis at this stage was characterised by identifying which aspects of data was being captured, what was interesting about the themes, and why themes are interesting.

In order to identify whether current themes contain sub-themes and to discover further depth of themes, it is important to consider themes within the whole picture and also as autonomous themes. The researcher conducted and wrote a detailed analysis to identify the story of each theme and its significance as illustrated in the results chapter. By the end of this phase, the researcher defined what current themes consisted of, and explained each theme in a few sentences. It is important to note that the researcher began thinking about names for themes that will give the reader a full sense of the theme and its importance. According to Braun and Clarke, (2006) the researcher conducting thematic content analysis should attempt to go beyond surface meanings of the data to make sense of the data and tell an accurate story of what the data means.

4.9.6 Phase 6: Producing the report

In the result chapter, the final themes were reviewed and the researcher began the process of writing the final report, illustrated in the next chapter. While writing the final report, the researcher decided on themes that made meaningful contributions to answering research objectives which should be refined later as final themes. The researcher presented the dialogue connected with each theme in support of increasing dependability through a thick description of the results. The goal of this phase was to write the thematic content analysis to convey the complicated story of the data in a manner that convinces the reader of the validity and merit of the research analysis. A clear, concise, and straightforward logical account of the story across and with themes is important for readers to understand the final report. The write up of the report contains enough evidence that themes within the data were relevant to the data set. Extracts were included in the narrative to capture the full meaning of the points in analysis. The argument was in support of the research problem statement and objectives of the study. The final step in the results also assisted in producing the explanatory model of challenging behaviour in persons with intellectual disability in the Capricorn District, Limpopo Province.

Analysis phases and their descriptions

Thematic analysis (Braun & Clarke, [2006](#): 87)

Familiarising with data

Transcribing data, reading and rereading the data, noting down initial ideas.

Generating initial codes

Coding interesting features of the data systematically across the entire data set, collating data relevant to each code.

Searching for themes

Collating codes into potential themes, gathering all data relevant to each potential theme.

Reviewing themes

Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map.

Defining and naming themes

Ongoing analysis for refining the specifics of each theme and the overall story that the analysis tells, generating clear definitions and names for each theme.

Producing the report

The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis.

Content analysis (Elo & Kyngäs, [2008](#): 110)

Preparation

Being immersed in the data and obtaining the sense of whole, selecting the unit of analysis, deciding on the analysis of manifest content or latent content.

Organising

Open coding and creating categories, grouping codes under higher order headings, formulating a general description of the research topic through generating categories and subcategories as abstracting.

Reporting

Reporting the analysing process and the results through models, conceptual systems, conceptual map or categories, and a story line.

Table 4.1. Processes of data analysis in thematic analysis and qualitative content analysis-Criteria for good TCA

4.10. Development of an explanatory model

In the present study, the development of an explanatory model for challenging behaviour will be in accordance with the general procedure for good theory-building. According to Wacker (1998), a good general procedure in theory-building should aim to answer the “... *questions of who, what, when, where, why, how, should, could and would*” (p.368). In order to address these questions, Wacker (1998) suggests that theory-building should be in accordance with the following four procedures that would be applicable after the themes have emerged:

- **Definitions of variable:** This refers to variables that would have emerged from the views of parents and teachers of persons with intellectual disabilities.
- **Limiting the domain:** In this case means when and where these challenging behaviours occur.
- **Relationship (model) building:** The general procedure for good-theory building, aim to answer the questions of why and how does the challenging behaviour happen.

Theory predictions and empirical support: Based on the circumstances mentioned above, the prediction can be useful in a making plan for future developments and possibly give the most relevant virtues to ensure that any theory developed is good.

The four procedures outlined above are illustrated in the table below (See Table 2) as conceptualised by Wacker (1998).

A general procedure for theory-building and the empirical support for theory

	Purpose of this step	Common question	'Good' theory virtues emphasized
Definitions of variables	Defines who and what are included and what is specifically excluded in the definition.	Who? What?	Uniqueness, conservation
Limiting the domain	Observes and limits the conditions by when antecedent event and where the subsequent event are expected to occur.	When? Where?	Generalizability
Relationship Building	Logically assembles the reasoning for each relationship for internal consistency.	Why? How?	Parsimony, fecundity, internal consistency, abstractness
Theory predictions and empirical support	Gives specific predictions. Important for setting conditions where a theory predicts. Tests model by criteria to give empirical verification for the theory. The riskiness of the test is an important consideration.	Could the event occur? Should the event occur? Would the event occur?	Empirical tests, refutability

Table 4.2 Outlines the general procedures for developing theory. J.G. Wacker, *Journal of Operations Management* 16 (1998) 368

The researcher in the present study was guided by Wacker's procedure in theory building in order to develop and articulate an explanatory model on challenging behaviour in persons with intellectual disabilities. Full details on how the explanatory model was developed in the present study will be fully explained in results chapter.

4.11. Quality criteria in qualitative research

The terms reliability and validity are often used to evaluate the value of research. However, it is argued that these criteria are essentially related to a positivist, or realist perspective of how we should view reality and knowledge (Willig, 2013). But all these criteria may not fit appropriately with qualitative research. For this reason, terms such as credibility, quality and trustworthiness have increasingly been adopted by qualitative researchers in order to assess value (Choy, 2014).

4.11.1. Trustworthiness: This refers to the demonstration that the evidence for the results reported is sound, and that the argument made based on the results is strong (Choy, 2014). According to Elo, Kääriäinen, Kanste, Pölkki, Utriainen and Kyngäs, (2014), trustworthiness entails the availability of rich, appropriate, and well-saturated data. In the context of the present study, the researcher ensured that the results of the study met the criterion of trustworthiness by making and keeping the field notes and a reflective journal through the process of the study in order to evaluate her position in the study and the processes involved. The aim therefore was to minimise factors that may create bias in the research findings. Furthermore, the process of research was outlined in detail, in respect of the processes of data collection, sampling, analysis and reporting.

4.11.2. Credibility: This quality criterion relates to whether or not there are faithful descriptions or interpretations of human experiences in the study (Ivankova, 2014). One way to facilitate credibility is to show sensitivity to the context in which the study was conducted (Yardly, 2000). To achieve this, the researcher ensured that she was aware of the wider context in which the research was situated. This involved familiarising herself with the literature on intellectual disability and immersing herself with the extant literature underpinnings of the TCA. This refers to linking the research study's results with reality in order to prove the certainty of the research study's findings. In the present study, credibility was achieved by reviewing and re-reviewing of data and different sources of data such as interviews with participants and use of their words as well as memos written, constant comparisons of the transcripts of data and the coded concepts and categories and participants checks (that is, respondents' validation of the information).

4.11.3. Confirmability: In this case, the researcher seeks to determine that findings of the study are solely shaped by the participants. Confirmability discusses the extent to which the results could be confirmed or verified by others. It also states to which degree the results are free from bias. To be able to achieve confirmability, the researcher took steps to attest that findings emerge from the data and not from my own predispositions. I had to record all participants' feelings in these research including their attitudes reactions during interviews to minimise bias and predetermined notions (Ivankova, 2014). For this

study, I relied on the raw data provided by the participants and I was as objective as possible in order to achieve confirmability.

4.11.4 Dependability: This quality criteria entails trustworthiness because it establishes the research study's findings as consistent and repeatable. Dependability is also attained when the results would be consistent if the study were to be imitated with the same participants and context. There is a disagreement in the literature regarding how to critic qualitative research and if it should be critiqued by the same criteria as quantitative research (Ivankova, 2014). To achieve dependability for the present study, I went through the code-recode method which entails the coding of the same research data in two separate times with a gestation period in between to compare the similarities in the results of the two codes.

4.11.5 Transferability: This refers the extent to which the validity of results can be applied to other settings and contexts. In this particular study, the researcher definitely wrote an extensive explanation of situations or context (Ivankova, 2014). This was achieved when the researcher provided a detailed description of the enquiry and participants were selected purposively, this facilitates transferability of the inquiry. Similarly, in the present study the researcher ensured that the results of the study met the criterion of transferability by providing a highly detailed description of the research situation and methods when reporting.

4.12. Ethical Considerations

The ethical considerations adopted for the study were premised on the ethical framework for clinical research (Emmanuel, Wendler, Killen, & Grady, 2004). As Emmanuel et al., 2004 succinctly puts it:

“... although poverty, limited health-care services, illiteracy, cultural and linguistic differences, and limited understanding of the nature of scientific research neither cause nor are necessary exploitation, they increase the possibility of such exploitation” (p.930).

4.12.1. Permission for the study

Prior to the commencement of the study, the researcher obtained ethical clearance from the University of Limpopo Ethics Committee (Ethical Clearance Certificate Number TREC/183/2018: PG) (see Appendix 2). Secondly permission was obtained from Limpopo Provincial Department of Education (see Appendix 5 for the permission letter).

4.12.2. Fair selection of participants

The participants were selected fairly to ensure valid representativeness to ensure scientific validity of the research. The participants in the study were carefully selected to minimize the risks of the research but enhance collaborative partnership and enhance social value. For this reason, the help of the principals in both schools were requested by the researcher to identify participants (parents) who met the inclusion criteria. Identified potential participants were then approached by the researcher and courteously request to take part in the study.

4.12.3. Informed consent

The principle of justice refers to equal share and fairness. This was adhered to in the study by ensuring that all the participants had the necessary information for informed consent. Prior to the commencement of the study, the researcher sought informed consent from the participants in the study (see Appendix 4).

Participants were made aware that their involvement in the study was entirely voluntary, and that they could decide not to answer certain questions or could terminate the interview or withdraw from the study altogether if they felt they were not able to handle the process without any consequences. Those who did not necessarily want to withdraw from the study but required a break from the interview so that they can deal with their emotions and who were still willing to continue later, were given that space and were treated with dignity. All this was done so that the participants' right to exercise their autonomy, as discussed by Wassenaar (2011), is observed and respected.

The researcher gave parents an option to be interviewed at their homes or in the teachers' classroom and the teachers in their own classrooms, depending on where they felt more comfortable. Privacy was ensured during the interviews. Only people with whom the participants were comfortable formed part of the interview. Such other people included parents and sibling/s of the parents. Other participants also had no problem having their child/children as part of the interview, and those children included those that have the disability and those without it. The interviews took place in the participants' home language. They were able to speak freely in a language they understand and are comfortable with.

4.12.4. Confidentiality and anonymity

Confidentiality entails that any information that the participants divulge is not made public or available to others. Participants were made aware that the digital recordings would be deleted after they have been transcribed. Consent was sought for anonymised quotes from participants to be used in the report and subsequent academic writings.

All the participants were informed of their right to confidentiality. All voice recordings, paper data (notes) and transcribed data were kept confidential by the researcher. Participants were treated with full care and respect and their identity is hidden in the transcribed data. The children are also treated the same way. Their real names are not revealed in the transcribed data. Fictitious names are used to identify them instead. Throughout the process, all the information has always been saved under password protection on a laptop and locked away where only the researcher had access. The information participants shared with the researcher, including sensitive information like their HIV/AIDS status, was also respected and kept confidential.

4.12.5. Privacy

In this study, the researcher ensured that when participants described their notions of intellectual disability, the information is not be divulged. The researcher ensured that the dignity and respect of all participants is maintained and valued, assuring them that data obtained from their involvement in the study will only be used to accomplish research objectives. Privacy was maintained by the researcher throughout the process.

4.12.6. Right to withdraw

The research participants were given the right to withdraw from the study should they so wish. The researcher ensured that participants were treated fairly by explaining their rights in terms of voluntary participation, confidentiality, identity protection and all other possible questions they had. Participants were selected purely based on the research requirements and not because of any other factors. Everyone had a fair chance of being part of the study if they met the requirements and about the possibility of withdrawing at any stage. These efforts addressed beneficence, a concept in research that seeks to encourage researchers to prioritize participants' welfare in any research (Van der Riet & Durrheim, 2011).

4.12.7. Debriefing of participants

The researcher also adhered to the principle of beneficence (not causing any harm to the participants). Because of the sensitive nature of the study, all participants that may show some emotional problems arising from this study will be referred for psychological intervention at the nearest hospitals or clinics to offer them service. The researcher was also bound to terminate the interview if she felt that the participant was becoming distressed. After the interviews debriefing were also offered to participants, if required. There was, however, no participant who portrayed adverse emotional reaction during the entire data collection process. No interviews in this study were terminated.

4.12.8. Beneficence

There were no obvious direct benefits for the parents and teachers who formed part of the study. Participants were not paid any money or any sort of reimbursement for participating in the study. This was explained to them during the initial visit to their homes. However, the study was necessary and important. The information gained through this research study may be used to positively impact in their lives with their children and/or learners with ID. Future teachers, parents and children in their position may also be positively impacted. The research may add value to the community in general by, among other things, helping the community learn more and be aware of the disability and its impact. This could happen as participants receive the platform to talk about their experiences of

having and living with children with ID. Such platforms will hopefully make the community more conscience and aware of intellectual disability and its impact on those affected; something that would likely mean more support for families affected by intellectual disability.

Interventions (such as community or home-based health care programmes which should involve specific personnel like traditional healers, pastors, occupational therapists and nurses) will hopefully come from concerned parties such as social development agencies in the future. Such parties can initiate measures such as teaching coping strategies to help the parents and teachers deal with or manage the challenges they face from raising children with ID.

Participating in this study was also hopefully a positive step towards breaking the tradition that exists particularly in South African villages of avoiding conversations and myths related to intellectual disability, as explained by Laas (2010). The end of this practice will mean that the shame, myths and stigma associated with ID will be reduced, benefiting these participants who often find themselves and their families cast away from society because of this disability in the family. Also, other researchers will hopefully be inspired to do further research on the topic in other South African rural and township areas, thereby addressing the issue of inadequate research on ID in these areas.

4.13. Conclusion

The methodology that was followed in the study was outlined in this chapter. The quantitative and qualitative research paradigms were also deliberated, the research approach and design of the study as well as the methods used to collect and analyse the data were presented. Finally, quality issues in research were discussed followed, lastly, by a presentation of ethical considerations observed in the study. The next chapter will present the results of the study.

CHAPTER 5

FINDINGS

This chapter presents an analysis of the data. In the first part of the chapter, the demographic characteristics of the participants are presented. In the second part, the four superordinate themes that have emerged from thematic analysis of the twenty three participants are presented. The related subthemes are also presented in the section. In the third part results are integrated so as to communicate the psychological essence embedded in what parents and teachers understand to be challenging behaviour in persons with intellectual disability.

PART A: DEMOGRAPHIC DETAILS AND SUMMARY OF INTERVIEWS

5.1. Demographic profile of the participants

The study is comprised twenty-three (23) participants who are 12 parents and 11 teachers of persons with intellectual disabilities portraying challenging behaviours, residing within the Capricorn District of the Limpopo Province (see table 1 and 2 for demographic details of participants). They were all from the Pedi language groups in the Province of Limpopo however 80% of the participants were fluent in English and elected to take part in the interview using English. The participants' ages ranged from 26 years to 59 years. Their mean age was 41 years. The majority of the parents' participants (50%) had secondary school education, 20% primary school education, and 30% having tertiary school education. Most of the participants (65%) were single, 25% married while the other 20% were widowed. In terms of employment, 50% were unemployed, 40% were self-employed 10% had full-time employment.

The following table summarises the demographic data of the parents' participants (table 5.1a).

Participant	Age	Marital Status	Education Qualification	Gender	Occupation
A	52	Single	tertiary	Female	employed
B	43	married	matric	Female	self-employed
C	26	Single	matric	Female	unemployed
D	58	married	primary	Male	unemployed
E	40	married	tertiary	Female	unemployed
F	36	Single	matric	Female	self-employed
G	59	Widow	tertiary	Female	self-employed
H	41	Single	primary	Female	unemployed
I	44	Widow	matric	Female	employed
J	56	Single	matric	Female	unemployed
K	37	Single	matric	Female	unemployed
L	31	Single	primary	Female	self-employed

5.1.1. Participant A

Participant A is the biological mother of a 16-year boy who has intellectual disability and portrays challenging behaviour. Participant A is a single mother aged 52, comes from *Molepo* village, has a college diploma and is employed at the department of Road and Transport. She mentioned how her child is always confused and loves screaming, speaks using unfamiliar language mostly when he starts hearing voices and is habitually in and out of touch with reality. She mentioned that he sometimes feels restricted like something is choking him and he sometimes has minimal control over his body. She also stated the aggressive and wild behaviour, her son would sometimes get lost and come back after

few days. She mentioned that she believes that her child has been bewitched as a child, because he was going to make their family rich, but they made sure that they take his mind and reasoning capabilities away from him. She also states that they take him sometimes to use him, hence he sometimes doesn't return home. She mentioned that she was informed to take her child to Moria so that they could cure him of his intellectual disability. She indicated that she agreed to go to Moria because she was suffering, confused and wanted to see her son get well. She mentioned that after going to *Moria* her son's condition did not change. This clearly shows that she lacked belief in ZCC Church. Participant A reported that her son gets better when they take him to sangoma. This also proves that she has got a strong belief in traditional remedies and sangomas. She is a strong believer of cultural rituals and practice.

5.1.2. Participant B

Participant B is the biological mother of 12- and 7-years old boys who have intellectual disability and both portray challenging behaviour. Participant B is married with 4 kids and 2 of them have intellectual disability. The mother aged 43, comes from *Ga-Rampheri* in *Molepo* village. The mother is self-employed. She mentioned that her children always hear voices and see people that she cannot hear nor see but could be understood by people sangomas. She also stated that to other people who don't understand their situation, they perceive them as being too hyperactive and aggressive. She mentioned that this is caused by heredity, their experiences and actions resonate that of her late grandma who used to be a sangoma. She believes that they behave like that because of their spiritual calling, they are supposed to be sangomas. Participant B believes that because of her cultural background and knowledge of what might be happening, understands that her children have spiritual calling, hence they reveal challenging behaviours. She believes that her children took this gift from her grandmother.

Participant B mentioned how the traditional ways of doing things. She discussed her reliance of indigenous way of living and that traditional belief system was important to her. She narrated during the interview that throughout her entire life she has always relied on her traditional belief because they were always taught by their grandmother. She mentioned that if she had any problem the first people, she would usually consult with will

be a traditional healer or *sangoma*. She mentioned that they have special supernatural powers to see things that any ordinary people cannot see, because she believes that her sons have ancestral calling. Participant B mentioned that she still relies much on the traditional doctors for many things in his life. She indicated that the only reason she still gets medication from the hospital is because of the medical reports they want at school but nonetheless she will not stop consulting with the *sangoma* because she doesn't believe that her sons are mentally sick. She believes that it is ancestral callings coming in a form of intellectual disability because they take time to act on it.

The participant mentioned that a traditional ceremony will be conducted to connect her sons with their ancestors regarding their illness. She emphasised that this is a crucial element in her clan because it serves to connect both the living and the dead in the entire clan. She revealed that when anything significant happens in the family or the entire clan the ancestors or spirits must be notified about it through the spilling of blood of an animal. She also mentioned that this has been the practice in their family for many years whenever anything of significance happens.

She is a strong believer of cultural rituals and practice. She believes that nurses and teachers lack knowledge about African spirituality, customs and beliefs because they are more focused on western medication that she feels are not helpful.

5.1.3. Participant C

Participant C is the biological mother of a 9 year of girl who has intellectual disability and portrays challenging behaviour. The mother aged 26, comes from Boyne. The mother is a university drop out. She is a strong believer of ZCC *Moria* church. She doesn't refer to her child as her child but calls her by name because she was sexually abused by her father and later got pregnant. The daughter's pseudo name for the study is CC. It does appear that participant C perceive challenging behaviour from her child in terms of stereotypical behaviours, inappropriate sexual behaviours, violence/aggressiveness/fighting, over-eating, inability to control bowel movement, lack of respect amongst children, being mischievous/naughty, hyperactivity, children stealing, stubborn, lying and lacking respect. Participant C believes that because of the immoral way or taboo the child was conceived, her child is a curse from the ancestors.

She believes that the ancestors are really confused with the child; hence the child is cursed with intellectual disability because her child is also her father's child. Participant C's religiosity is interesting in that she discussed that she had always been religious and surely devoted to ZCC church. She also discussed her reliance on the ZCC church, particularly the tea (church practice) that the church priests and elders make for sick people. The instructions she gets from the church really help her child deal with challenging behaviour

5.1.4. Participant D

Participant D is the biological father of 12 children of whom 7 have intellectual disability and portrays challenging behaviour. Their mother aged 47, has also been diagnosed with intellectual disability. Their father is 58 years of age and comes from *Sethokgweng*, a village in *gaMolepo* area next to *Moria*. The father has worked at the mine and is now retrenched. Participant D is a member of the ZCC. He, however, stated that he started going to the ZCC after realising that most of his children are diagnosed with intellectual disability. He also believes that his children with intellectual disability are a sign from the ancestors proving his wife's promiscuity. He mentioned that she was also cursed with intellectual disability as a punishment from the ancestors.

Participant D perceives challenging behaviour as behaviours that are exhausting and extremely hard for him to manage. The fact that he has 7 children together with his wife in one household who are diagnosed with intellectual disability can be very difficult to manage.

He mentioned that prior to this he used to only rely on traditional methods to cope with problems and managing the children's challenging behaviour. He indicated that he consults with traditional doctors because they know how to deal with bad spirits, uses the tea from *Moria* and the medication they provide the children from the hospital.

5.1.5. Participant E

Participant E is the biological mother of an 11-year-old girl who has intellectual disability and portrays challenging behaviour. Participant E is a married woman aged 40, comes from *Mankweng*, Unit C, has a computer science degree and is employed. Participant E

mentioned that her child was born with intellectual disability. The doctor properly explained and prepared her to be able to deal with my child. She mentioned that her child do most things (she has seizures, motor skills impairment, anxiety, stereotypical behaviour, aggressiveness, crying hysterical when she cannot get what she wants, hyperactive, like to bite her clothes) she believes they are normal challenging behaviour symptoms from children who suffer from intellectual disability. Participant E strongly believes that these result from abnormalities of genes inherited from her father's side of the family. Other psychological factors such as stress caused by the abuse she suffered from her husband during her pregnancy. Participant E mentioned how she understands that her child has a medical and genetic condition. She believes that doctors are really doing a great job assisting her daughter. She is a strong believer of HealthCare support and a Christian.

Participant E clearly states that she gets tremendous support from the pastor in her church, praying for her daughter. Participant E also reported that he also trusts on the support of his children and the healthcare staff and the teachers at special schools.

5.1.6. Participant F

Participant F is the biological mother a 13-year-old girl who has intellectual disability and portrays challenging behaviour. Participant F is a single mother aged 36, comes from Solomondale, has matric and is employed. Participant F understands challenging behaviour as demonic attacks or curse. She mentioned that her child always gets demonic attacks and it is visible that he is possessed when he gets aggressive and angry. She mentioned that she is certain that her aunts from her father's side made her to be a useless human being, if she is not energetic, angry or aggressive, she would only be quiet, salivating, urinating and pooping on herself. She declared that they made my child to be useless because they never loved her mother and her siblings. She believes that someone has a remote in their hands to control her child. Participant F believes that the cause of her child illness is due to witchcraft and being cursed by her relatives. Participant F is a strong believer of Christianity. She clearly states that she gets motivated by praying and getting support from the pastor in her church, praying for her daughter to get better.

5.1.7. Participant G

Participant G is the biological mother of a 21-year-old boy who has intellectual disability and portrays hallucinations and terrifying involuntary movements as challenging behaviour. Participant G is a widow aged 59, comes from Mankweng (Toronto), teaching diploma and is employed. She is a strong believer of Traditional healing. She mentioned that challenging behaviours are brought by people of the night. She believes that her child has been used by people who have been tormenting them since they were kids. She stated that her child's mind is always confused, and that he is used at night. Participant G mentioned that a few months after discovering that her child has epilepsy, he started to behave strangely, screaming, shouting and at times could not speak. She mentioned that he always sees things at night and wants to run away from them, he screams when he sees things that we cannot see and hearing things that we cannot hear. She also stated that when their sangomas comes to rescue him, he behaves aggressively like an animal or snake as if those things are fighting with the sangomas. She believes that his illness is due to the things that witches try to do to him and not prospering. Participant G clearly states that she relies heavily on traditional remedies from sangomas.

5.1.8. Participant H

Participant H is the biological mother a 17-year-old boy. Participant H mentioned that they have ancestral calling in their family background, which gets wrongly confused with having intellectual disability. She has been trying to run away from this ancestral calling which is in their family traditions and background. Participant H is a single aged 41, comes from *ga-Kama* a village outside *Mankweng* and she is unemployed. She stated that in their family they have aggressive spirits that are tormenting them to do things that people assume that they are crazy. She mentioned that they do these extra ordinary behaviours because they are extraordinary people and that they have extraordinary powers, they hear voices from their ancestors and see them in spirit. She mentioned that when they are in spirit, normal people don't understand, and they inaccurately confuse them with being crazy. Participant H tends to perceive challenging behaviour of her child as behaviours that are caused by heredity of ancestral calling from their grandmother because she also has ancestral spirits. She mentioned that she tries to ignore these

spirits by going to church because her partner doesn't believe in sangomas and forces her to go to church, but these spirits keep on haunting her together with her son. She mentioned that pastors would say that they have demons inside them, and she keeps on telling them that her grandmother was a traditional healer

She is a strong believer of Traditional healing. Participant H clearly state that she believes in traditional ways remedies and healing because of her background but she has been hiding away from them because she has a partner who doesn't believe in traditional remedies.

5.1.9. Participant I

Participant I is the biological mother a 20-year-old girl who has intellectual disability and portrays challenging behaviour. Participant I is a widow aged 44, comes from Boyne, has matric and is employed. Participant I understand challenging behaviour as mental illness that includes demonic attacks or evil curse/spell. She mentioned that her child always gets demonic attacks and it is visible that he is possessed when he gets aggressive and angry. She mentioned that her child has been cursed by people. She believes that it could be someone very close to the relative. Participant I believe that the cause of her child illness is due to witchcraft. Participant I is a strong believer of western medicines from hospital, ZCC member and she also believes in traditional healing. She clearly states that she copes by giving her child medication from church, getting her tea from church, and consulting with the sangomas for healing.

5.1.10. Participant J

Participant J is the biological mother a 27-year-old boy who has intellectual disability and portrays challenging behaviours of screaming, yelling and enjoys stereotypical behaviours. Participant J is a single mother aged 56, comes from *gaDikgale*, a village next to Mankweng has matric and is unemployed. Participant J understands challenging behaviour as a mental illness that was caused by stress. She mentioned that her child has intellectual disability because she had tremendous stress of losing her child's when she was pregnant. She mentioned that she takes good care of her child and always packs medication for her and gives him medication when necessary. She is also a ZCC

church member and she believes the church is very much helpful and supportive towards her child.

5.1.11. Participant K

Participant K is the biological mother an 11-year-old boy who has intellectual disability and portrays challenging behaviour. Participant K is a single mother aged 37, comes from Solomondale, has matric and is unemployed. Participant K understands challenging behaviour as an unusual behaviour, with hallucinations. She mentioned that her child always sees and hears things that no one can see or hear. She believes her child was bewitched, cursed or punished when he was a baby. She declared that she went to traditional healers and they confirmed her child to have ancestral calling. Participant K mentioned that she wants her child to be ok first before he becomes a sangoma.

5.1.12. Participant L

Participant L is the biological mother a 13-year-old girl who has intellectual disability and portrays challenging behaviour. Participant L is a single mother aged 31, comes from *Sekgweng* a village in *gaMolepo* and is self-employed. Participant L understands challenging behaviour as mental illness that is not understandable and very difficult to manage. She feels her child challenging behaviour is due to lack of money because they stay far from the hospital and they are from a low economic status. She mentioned that she is energetic, angry or aggressive, screams, salivating, urinating and has a high sexual libido for her age. Participant L is a strong believer of Christianity. She clearly states that she gets motivated by praying and getting support from the pastor in her church, praying for her daughter to get better.

The following table summarises the demographic data of the teachers-participants (table 5.1b).

Participant	Age	Years of Experience	Gender	Employment Status
M	46	11	Male	Bana ba Thari
N	41	7	Female	Bana ba Thari
O	54	8	Female	Bana ba Thari
P	41	7	Female	Bana ba Thari
Q	47	12	Female	Bana ba Thari
R	52	19	Female	Benedict & Hope
S	39	5	Female	Benedict & Hope
T	56	5	Male	Benedict & Hope
U	36	2	Female	Benedict & Hope
V	38	3	Male	Benedict & Hope
W	41	8	Male	Benedict & Hope

5.1.13. Participant M

Participant M is 46 of age and has 11years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. He is based in Bana ba Thari special school. He believes that challenging behaviours are behaviours that are considered abnormal, weird not easy to understand or even cope with. He

mentioned that some learners have this challenging behaviours because they are sangomas, he stated that they see and hear things that only they can sense and they also move and scream differently when they are in the state of seeing and hearing things. He mentioned that some are avoiding their gifts of ancestral calling hence they suffer from these behaviours. He mentioned it to be curses or bad luck from ancestors for avoiding them. He also stated that people must follow their traditions and go to sangomas to help them with ceremonies of initiation to become a traditional healer. He mentioned that sangomas will help them connect them with their ancestors for their healing.

5.1.14. Participant N

Participant N is 41years of age and has 7years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in Bana ba Thari special school. Participant N understand challenging behaviour as behaviours that are difficult to manage e.g. aggressive behaviours, vulgar, hallucinations, bullying, cannot talk properly, uncontrollable behaviours and abnormal sexual behaviours. She also mentioned that they are also called shocking or abnormal children, and some would be killed in her village.

Participant N tends to perceive challenging behaviour of her learners as behaviours that are caused by heredity, witchcraft, medical conditions and environmental factors. She mentioned that most of them are born like that because it is God's will; some of them is heredity because their parents are just like them. Some families have children with intellectual disability as a generational curse, some are bewitched because they are born well and then they change when they grow up or maybe the child went somewhere and was used for witchcraft and those things were reversed back to them. Some mothers could be physical, psychologically or emotionally abused when pregnant and can produce a child with intellectual disability. Some mothers smoke and drink during pregnancy and seasonal change can cause them to get more confused. Participant N mentioned how she believes that challenging behaviour could be as a result of witchcraft, medical and psychological conditions, and environmental factors. Participant N clearly state that she finds Medical health care support, traditional methods and religious methods combined would help cope with challenging behaviour.

5.1.15. Participant O

Participant O is 54years of age and has 8years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in Bana ba Thari special school. She explains challenging behaviours as behaviours that includes fighting, vulgar, aggressive behaviours and she believes that their IQ makes them behave like that way. Participant O tends to perceive challenging behaviour of her children as behaviours that are caused by heredity, witchcraft, medical conditions and environmental factors. Participant O mentioned how she believes that challenging behaviour could be as a result of witchcraft, ancestral punishment or will of God. Participant O clearly state that she finds Medical health care support, traditional methods and religious methods combined would help cope with challenging behaviour. Centres for older scholars in special scholars should be created.

5.1.16. Participant P

Participant P is 41years of age and has 7years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in *Bana ba Thari* special school. She did illustrate that she perceives challenging behaviour when the child is hyperactive, bully, can't even listen and talk. She mentioned that they also call it madness or craziness, and some are also epileptic. She mentioned that challenging behaviour of her students are behaviours that are caused by heredity, witchcraft, medical conditions and environmental factors. It might be heredity, medical conditions, abuse in the family also makes children to have behavioural problems and makes the child bully. Participant P clearly state that she finds Medical health care and government support helpful to help their students cope with challenging behaviour. She stated that they need proper medical help; they need to take their medication regularly and they need facilities from that government that will help them in terms of training to become better human being in the future.

5.1.17 Participant Q

Participant Q is 47 years of age and has 12 years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in *Bana ba Thari* special school. Participant Q mentioned that Challenging behaviours are behaviours such as bullying, fighting, inappropriate sexual behaviours, sometimes they steal, and they also get irritated when they can't get what they want. She also mentioned that they inherited this from their family genes. She revealed that they learned fighting from their abusive parents. She also mentioned that black magic could also be the cause, because sometimes children of the same parents would all have intellectual disability and others would develop the illness when they are older. She mentioned that some are born with it by the will of God. Participant Q believes that Health professionals (psychologists, social workers and nurses), pastors and traditional healers should work together to help persons with intellectual disability to cope better with their challenging behaviours.

5.1.18. Participant R

Participant R is 52 of age and has 19 years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in *Bana ba Thari* special school. Participant R understands challenging behaviour as behaviours that are difficult to explain, behaviours that makes people change aggressively, they look extremely terrified because they probably saw things they were not supposed to see and they look extremely tired when they are in that state. These children even say that they could move out of the class through walls or the roof. Participant R mentioned that challenging behaviour is caused by curses of witchcraft. She mentioned that witchcraft is there, and it is alive, these kids could be used abnormally by people and they would start behaving differently. Participant R clearly state that she finds traditional and religious healing methods combined would help cope with challenging behaviour. She mentioned that a child should be protected by either traditional healers or pastors when they are born. She mentioned that these things are real, and Africans don't talk about their African/cultural ways of doing things. She pointed out that white people (Eurocentric view) take these things from us, then interpret them differently and categorise them in their own knowledge.

5.1.19. Participant S

Participant S is 39 of age and has 5years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in Benedict & Hope special school. She mentioned that challenging behaviours occurs because these children could be like this because their families practice witchcraft. She mentioned that most of these students have siblings with the same condition. She states that it appears that there is something wrong with that family. She also mentioned that as Africans when kids scream and shout for no reason, they believe they see things and their scream looks like they are running away from something. She also stated that they discover these things in their classes that these kids see and hear things that we don't see. She also mentioned that these kids are just tormented in their minds. Participants S clearly state that she finds traditional methods relevant to help persons with intellectual disability cope with challenging behaviour. She mentioned that they need to see traditional healers and that there is need more traditional healers in communities. She mentioned that people took white people' healing too much, they cannot even see what we are struggling with. We ran away from our traditions. Eurocentric healings are failing us because they don't understand what we go through, they are not familiar with what we deal with daily. We must follow our roots. This intellectual disability is too much in our culture now because we ran away from our culture. We need to go back to our African ways of healing.

5.1.20. Participant T

Participant T is 56 of age and has 5years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. He is based in Benedict & Hope special school. He believes that challenging behaviours are behaviours that are considered abnormal. He mentioned that challenging behaviours are signs of a curse and witchcraft. He stated that the family should have probably tried to bewitch someone, and those curses are coming back to them through that abnormal child as a punishment from God. He believes that persons with intellectual disability are possessed with bad spirits, curse and bad luck, they might also be bewitched or they themselves are witches who failed at a mission. He mentioned that they are tormented with spirits that

are really bothering them on a day to day basis. He stated the remorse he has for them because he feels they don't enjoy anything because they are always fighting with things in the spirit. Participant T clearly state that he finds traditional methods of healing would help cope better with intellectual disability. He believes that they need sangomas for cleansing that will help them to heal.

5.1.21. Participant U

Participant U is 36 of age and has 2 years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. She is based in Benedict & Hope special school. It does appear from these extracts above that participant U understand challenging behaviour as behaviours that are difficult to for them to understand, cope and manage. He mentioned that Challenging behaviours are behaviours that include aggressiveness, anger, fighting, stereotypical behaviours and some other abnormal things that these kids do. He even mentioned that he believes that complications at birth, medical conditions and genetic conditions or heredity could also cause this people to have intellectual disability that would result in portraying signs of challenging behaviour. He strongly believes that it is because of God's will because he created these learners to have intellectual disability. Participant U clearly states that he finds Religious methods and medical health healing methods more helpful to cope with challenging behaviour. He clearly stated that he doesn't want to talk about witchcraft or traditional healing methods he is being recorded and the department of education might have issues with him. He mentioned that people should believe they have intellectual disability because of the will of God and that they should believe it to avoid accusing wrong people. This clearly defines that he believes in witchcraft and traditional healing but doesn't want to talk about them because judging with the number of years of experience, he just started working and he probably feels, talking about witchcraft would jeopardise his job. I tried to switch off the recorder hoping that he would tell me how he really feels but he refused.

5.1.22. Participant V

Participant V is 38 years of age and has 3years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. Participant V

understand challenging behaviour as behaviours that stem from ancestral calling, but the learner or family would hide that the child is a traditional healer or refuse the child to become a traditional healer. Participant V mentioned that behaviours that are caused by witchcraft or heredity of the ancestral calling background in the family. He also mentioned that for some is because of inheriting ancestral calling from their family background and some see things at night while they are going to practice witchcraft in other people's houses, when real witches find them, they shut their mouth with intellectual disability to confuse them with demonic attacks. He also stated that other people would want to bewitch you by using other people's children and when they find that your house protected then the child would have intellectual disability because they would be cursed. Participant V clearly states that she finds traditional healing methods more helpful to cope with challenging behaviour.

5.1.23. Participant W

Participant W is 41 of age and has 8 years of experience working at special schools of persons with intellectual disability and portrays challenging behaviour. He is based in Benedict & Hope special school. Participant W perceives challenging behaviour as behaviours that includes hallucinations, involuntary movements seizures, motor skills impairment, anxiety, stereotypical behaviour, aggressiveness, crying hysterical, hyperactive and sexual behaviours. Participant W mentioned that challenging behaviours can be caused by witchcraft or a curse, ancestral calling inherited from their family background. She mentioned that some God made them to be like that, it was only natural that they were born like that. She also mentioned that others would be caused by heredity because some family members might have it. She stated that environmental factors also play a huge role in the cause of challenging behaviours due to poverty and dysfunctional families. She mentioned the medical conditions a child could inherit while growing up e.g. measles, polios and other things because those can damage the brain. Participant W also mentioned how she believes that challenging behaviour could be as a result of God's will and she believes that they must go to church and get spiritual awakening because they are from God and they belong to him. Participant W believes that with the government support, medication, psychologists, nurses, doctors, pastors and

traditional healers must always be available in schools to help learners cope with challenging behaviours.

PART B: EMERGING THEMES

5.2. Phase 3 - Searching for themes

Themes that emerged from the data shared by the twenty-three participants are presented in this section in accordance with phase 3 steps of data analysis as presented in the methodology section. The themes are illustrated in a tabular form (see Table 5.2) before they are presented in detail

Themes	Understanding of challenging behaviour	Beliefs about causal explanation of challenging behaviour	Interventions to cope with challenging behaviour
Sub-themes	<ul style="list-style-type: none"> • Unusual behaviours/Involuntary movements/Spirits moving in the body • Hallucinations • Ancestral calling • Demonic Attack/possessed with evil spell spirits • Mental illness <p>Characteristics of CB</p> <ul style="list-style-type: none"> • Aggressiveness (screaming, yelling, shouting, fighting) • Self-injurious behaviours • Stereotypical behaviours • Inappropriate sexual behaviour • Confusion <p>Inability to care for oneself</p>	<p>Supernatural factors</p> <ul style="list-style-type: none"> • Witchcraft/Black magic • Curse/Generational-curses/Bad luck • God's will <p>Bio-medical factors</p> <ul style="list-style-type: none"> • Heredity/genetic conditions • Problems during pregnancy • Problem during childbirth and after childbirth <p>Psychosocial/Environmental factors</p> <ul style="list-style-type: none"> • Stress • Abuse/ Family conflicts • Death <p>Socio-economic factors</p> <p>Poverty (Lack of education & Unemployment)</p>	<ul style="list-style-type: none"> • Religious methods/ Christianity • Traditional methods <p>Reliable influences (Healthcare staff, community support, family support, NGO's and government support)</p>

Table 5.2: Themes and subthemes that emerged from the study

5.2.1. Theme1: Understanding of challenging behaviour

When the respondents were asked to explain their notions of caring for their intellectually disabled children and challenging behaviours they are faced with, their explanations showed some understanding of challenging behaviour. The knowledge was apparently gained through experience with their own intellectually disabled children. The participants in the study mentioned challenging behaviour based on their own belief background. Most of the participant mentioned challenging behaviour from a spiritual perspective.

5.2.1.1. Unusual behaviours

The findings in this study reveal that challenging behaviour is observed as unusual behaviours that involves involuntary movements or spirits moving inside the body. This is revealed in the responses below:

“He sometimes feels restricted like something is choking him and he sometimes has minimal control over his body.” (Participant A, female, 52yrs)

“All I can tell you is that I live in a chaotic house, there is definitely no order. When you try to fix this one, the other one is a problem. There is a lot of things happening in this household, they really don’t make any sense to me. My house is like a horror movie at times....a mad house with things that are happening here.”
(Participant D, male, 58yrs)

“He also walks in some funny movements when he is in that state.” (Participant K, female, 37yrs)

“I really don’t even know where to begin because it is just a total mess, my child portrays behaviours that are just too confusing for me to even know what to do.”
(Participant L, female, 31yrs)

“Some of these behaviours make them move like snakes as if they have spirits of snakes or animals in them.” (Participant T, male, 56yrs)

Based on the above extracts, it does appear that participants tend to describe challenging behaviour as behaviours that are unusual and confusing to understand.

5.2.1.2. Hallucinations

The findings in the study uncovers that challenging behaviour is witnessed as hallucinations. Some participants alluded that:

“My child is always confused and loves screaming. He usually speaks using unfamiliar language mostly when he starts hearing voices and is habitually in and out of touch with reality. He sometimes feels restricted like something is choking him and he sometimes has minimal control over his body.” (Participant A, female, 52yrs)

“My kids always hear voices and they always see people calling them to come and assist them, but unfortunately these things cannot really be seen with a naked eye. You must really have special powers to understand them.” (Participant B, female, 43yrs)

“My child always hears voices that I can’t hear. My child is always running in the streets doing things that we don’t understand as if someone has a remote in their hands just to control her.” (Participant E, female, 40yrs)

“He always sees things at night and wants to run away from them, he screams when he sees things that we cannot see and hearing things that we cannot hear.” (Participant G, female, 59yrs)

“These challenging behaviours are unusual behaviours; my boy always hears and sees things every time he would try to sit still. He would hurt himself because those voices or staff he sees disturbs him. He also walks in some funny movements when he is in that state.” (Participant K, female, 37yrs)

Moreover, these findings uncover hallucinations as challenging behaviours that are frightening, whereby they experience their children/leaners seeing, hearing or feeling things that don't exist outside their mind.

5.2.1.3. Ancestral calling

Participants’ perspective believes that a person has ancestral calling when they behave oddly. We also notice that some people become mentally ill because they are gifted to

take up the responsibility of healing other patients. The individual needs to go through the process of *go thwasa* in order to be healed from the signs and symptoms of ancestral possession and to become a traditional healer. The following responses highlight these observations:

“My kids always hear voices and they always see people calling them to come and assist them, but unfortunately these things cannot really be seen with a naked eye. You must really have special powers to understand them. My sons’ energies don’t really connect, because they get different massages at different times. To us it looks like they have too much hyperactivity and aggressiveness, but they are not. They only see things that we cannot see, and people would start interpreting their actions as being mad....do you agree? Medical drugs make it worse for my kids, they yell, scream and shout when the medication gets out of their system.”
(Participant B, female, 43yrs)

“This child has ancestral calling; I have been telling nurses and doctors that this child has ancestral calling. I also have these things. We have aggressive spirits that are tormenting us to do things that people assume that we are crazy. We do these extra ordinary behaviours because we are extraordinary people and that we have extraordinary powers, we hear voices from our ancestors and see them in spirit. When we are in spirit, normal people don’t understand, and they inaccurately confuse us with being crazy.” (Participant H, female, 41yrs)

“These behaviours seem as if the child is possessed with some evil spirits and for others the behaviour will occur because they have ancestral calling.” (Participant N, female, 41yrs)

“These challenging behaviours are unusual behaviours; my boy always hears and see things every time he would try to sit still. He would hurt himself because those voices or staff he sees disturbs him. He also walks in some funny movements when he is in that state, but it’s just are ancestors communicating with him.”
(Participant K, female, 37yrs)

“These challenging behaviours are ancestral callings that some of them have and they try to hide from them or maybe because their parents don’t tell us that these learners are traditional healers hence, they have abnormal behaviours that we call challenging behaviours.” (Participant V, male, 38yrs)

The participants believe that when an individual in their culture has an ancestral calling, he/she sometimes presents with symptoms and signs that are like those of a person with a mental illness/psychosis.

5.2.1.4. Demonic attack/Possession by evil spell spirit

Most participants reported that demonic attack can cause challenging behaviours among persons with intellectual disability. According to participants, demonic attacks alter the biological constitutions of persons with intellectual disability, thereby enabling the latter to acquire the capacity to host the demons. These reports indicate that participants believe that ancestral demons can cause challenging behaviour among persons with ID. Participants revealed that this attack could also be associated with witchcraft, the below extracts explain:

“My child always has demonic attacks and you can see that he is possessed when he gets aggressive and angry because his bodily movement changes. My aunts from my father’s side made him to be a useless human being.” (Participant F, female, 36yrs)

“These behaviours are brought by people of the night. This child has been used by people who have been tormenting us since we were kids. This child’s mind is always confused, they are using him at night. He always sees things at night and wants to run away from them, he screams when he sees things that we cannot see and hearing things that we cannot hear. When our sangomas comes to rescue him, his body behaves aggressively like an animal or snake because those things are fighting with the sangomas. His challenging behaviour is due to the things that witches are trying to do to him, they possessed him with evil spell. They probably want him dead.” (Participant G, female, 59yrs)

“These behaviours are weird and not easy for us to understand or even to cope with, now when the child comes to school and starts acting like they own the world, at times with the way they move, you can see that this child is really not a human being and when they are aggressive is as if something is telling them to fight or scream with the way that they will be heavily sweating. Some of these kids portray behaviours as if they were possessed by demonic attacks, because some of them even behave like they have evil spirits inside them, even by the way they move. It seems as if they enjoy being like that, because of the happiness they endure when they are in that state” (Participant M, male, 46yrs)

“These children could be like this because their families practice witchcraft. Most of these kids here also have siblings with the same condition. Can a parent have all three of her kids having this condition? It shows that there is something wrong with that family. As Africans when kids enjoy screaming and shouting for no reason, we believe they see things, and their screams looks like they are running away from something. We discover these things in their classes, they see and hear things that we don’t see. These kids are just tormented in their minds” (Participant S, female, 39yrs)

“Some of these behaviours make them move like snakes as if they have spirits of snakes or animals in them. Some of them behave like they are possessed with demons. It means that there is something that the family has done. The family should have probably tried to bewitch someone, and those curses are coming back to them through that abnormal child as a punishment from God. That is why they will never be treated like normal kids. There are some kids that are still locked in houses and they don’t bring them to special schools because they are ashamed that the child might expose them. They are always confused, aggressive and hear and see things that we just cannot see to assist them.” (Participant T, male, 56yrs)

Some participants stated that family members deliberately sent demonic forces to cause mental illness among their children due to family disputes. The above extracts illustrates that there is lack of trust between extended family members assuming that others will harm, deceive, take advantage or kill them generate the feelings of paranoia.

5.2.1.5. Mental illness

The study revealed that persons with intellectual disability develop mental illness that lead to challenging behaviours. Participants in the below extracts mentioned that mental illness affects emotions, mood and behaviour and can be suffered by people of all levels of intellectual ability.

“My daughter has been like this since birth. The doctor properly explained and prepared me to be able to deal with my child. My child do most things (she has seizures, motor skills impairment, anxiety, stereotypical behaviour, aggressiveness, crying hysterical when she cannot get what she wants, hyperactive, like to bite her clothes) those are normal challenging behaviour symptoms from children who suffer from intellectual disability .” (Participant E, female, 40yrs)

“Other children are just born like that because they suffer from brain injuries, down syndromes, cerebral palsy, epilepsy or even autism.” (Participant N, female, 41yrs)

“When the child is hyperactive, bully, can’t even listen and talk. We also call it madness or craziness. Some are also epileptic.” (Participant P, female, 41yrs)

“Challenging behaviours are behaviours portrayed by persons with intellectual disability and some might be born with the condition. They would just portray multiple mental disorders at one time.” (Participant W, male, 41yrs)

The above extracts illustrates that intellectual disability is understood as people having problems with learning, understanding, processing information and problem solving. Difficulties with communication, social skills and general living skills were also mentioned.

5.2.2. Characteristics of challenging behaviour

The respondents were further asked to describe their experiences of caring for their intellectually disabled children and challenging behaviours they are faced with. Self-injury, aggressiveness, stereotypical behaviours, inability to care for themselves, etc, common challenging behaviours that are more common in persons with intellectual disabilities. It

also emerged from the results of the study that there are many challenging behaviours that the parents and teachers deal with as reflected in the following extracts:

5.2.2.1. Aggressiveness (screaming, yelling, shouting, fighting)

This study explains that aggressiveness was identified as a type challenging behaviour used as a form of communication that allows individuals to terminate unwanted interactions with others or may provide access to preferred items or activities.

“When he struggles to do or say something, he gets more aggressive, and he starts fighting with everyone at home.” (Participant A, female, 52yrs)

“CC is very aggressive at school; she enjoys fighting for food and peers. She always takes people’s things and fight over them.” (Participant C, female, 26)

My child does most things, she likes to yell, scream and shout when she is not comfortable with the situation she is at. These are normal challenging behaviour symptoms from children who suffer from intellectual disability.” (Participant E, female, 40yrs)

“She always fights, aggressively and gets uncontrollably angry when she wants to run away from a particular situation.” (Participant I, female, 44yrs)

The above extracts illustrates that aggressiveness is stimulated by episodes of anger, violence and irritability. It seems as if aggressiveness might be their way of coping with discomfort or saying that something hurts.

“As Africans when kids scream and shout for no reason, we believe they see things, and their screams look like they are running away from something. We discover these things in their classes, they see and hear things that we don’t see hence they are always shouting and screaming. These kids are just tormented in their minds.” (Participant A, female, 52yrs)

“Some are aggressive, they yell, they shout, some are useless for themselves. They sometimes fight with things that cannot be seen.” (Participant D, male, 58yrs)

“You can see that this child is not a human being and when they are aggressive is as if something is telling them to fight or scream with the way that they will be heavily sweating.” (Participant M, male, 46yrs)

It was further indicated that aggressiveness, according to the participants cultural perspective mean that there is a tormented spirit that is disturbing the individual to behave aggressively.

5.2.2.2. Self-injurious behaviours

This behaviour also allows the persons with ID to initiate attention or interaction with others by hurting themselves. Self-injury was found to be behaviour that is more common among people with more severe intellectual disability as reflected in the following extracts:

“The minute the uncle locks him in the room to calm down, he starts to terribly hurt himself.” (Participant A, female, 52yrs)

“The challenging behaviours that I see in my class is aggressive behaviours that some would even self-mutilate when angry and hit themselves against the walls. They could even take chairs and hit their heads with it. These behaviours are usually done by those individuals with the IQ level of 70 or below.” (Participant M, male, 46yrs)

The above extracts indicate a number of factors causing someone to hurt themselves. It seems as if they self-injure when they feel they are not listened to, they have been told off or they have little or no choice about things The person might have no other way of telling you their needs, wants and feelings.

5.2.2.3. Stereotypical behaviours

The findings show that the repetitive behaviour patterns are also enjoyed by persons with intellectual disabilities.

“She has stereotypical behaviours, she sometimes copies people when they speak and does the same behaviour over and over to just irritate everyone.” (Participant C, female, 26yrs)

“Challenging behaviours is a mental illness that makes our children to scream, yell and repetitive actions. These children are really not well in their minds and because of that, they really cannot function like a normal child” (Participant J, female, 56yrs)

“Some of them really enjoy doing the same thing over and over until they get tired of it, hey would look for yet another thing to do again and again. They enjoy irritating behaviours.” (Participant O, female, 54yrs)

Some forms of self-injury might be part of a repetitive behaviour, an obsession or a routine. The person might be finding a task too difficult or overwhelming and they resort to repetitive behaviour to feel calmer.

5.2.2.4. Inappropriate sexual behaviour

Inappropriate sexual behaviour in persons with intellectual disability seems to be a very common challenging behaviour in persons with ID. The findings alluded that person with ID exhibit inappropriate sexual behaviour, such as public masturbation, or soliciting sex from minors or in public. They also force have sexual behaviour wherever they feel it is appropriate for them.

“She loves having sex with different boys at school even here at home, at times we thought these boys are taking advantage of her, but we later realised that she is the one wanting them.” (Participant C, female, 26yrs)

“Some siblings with the same condition have sexual intercourse with each other, on their own and sometimes with their mother, who also have intellectual disability.” (Participant D, male, 58yrs)

“She has concerning sexual behaviours as a child, she is always naked and seduces boys, she would even fight with you, if you stop her from doing those things in class. When she feels like she wants to do it, she wants to do it that time, I even have a scar to prove that she was once aggressive with me for refusing to let herself get naked.” (Participant L, female, 31yrs)

“Some of them have abnormal sexual behaviours, because they just want to have sex in class or even during lunch times, or even with young ones in school. It seems as if sexual thoughts are the only thoughts running through their minds.”

(Participant N, female, 41yrs)

It seems as if individuals with intellectual disabilities experience difficulty in interpreting behavioral cues within their social environments. This may in turn create negative outcomes for their expression of sexuality publicly.

5.2.2.5. Inability to care for oneself

The participants also indicated that there was impairment in adaptive behaviours, such as failure to take care of oneself, and limited adaptive functioning at home and at school. Some don't have people to care for them.

“She cannot even control her bowel movement; she smears faeces everywhere and acts like nothing has happened, always running around and confused without understanding what is really going on with her.” (Participant C, female, 26yrs)

“Some of them come from homes whereby the children and their mother have intellectual disability and their father is the only person who can take care of the family, you can imagine the chaos going on in those families ” (Participant N, female 41yrs)

“Most of them still needs to be properly taken care of on a daily basis because they cannot or struggle to take good care of themselves because their IQ is below 70.”
(Participant W, male, 41yrs)

It also emerged from the results of the study that persons with profound and severe levels of ID will struggle to care for themselves because of their inability to lead a fully independent life due to challenges communicating, taking care of themselves, or interacting with others.

5.2.3. Theme 2: Beliefs about causal explanation of challenging behaviour

The participants in the study demonstrated varied beliefs about causal explanations of the challenging behaviour. Among the participants in the study, beliefs about the causes of challenging behaviour often included a mix of both western (biomedical) and culturally specific beliefs and religious explanations.

5.2.3.1. Supernatural factors

The findings on the beliefs around perceived causes of challenging behaviour by the participants in the study included supernatural factors such as witchcraft, generational curses or badluck and God's will. This may be a reflection of the participants' cultural health attributions, beliefs, and practices.

5.2.3.1.1. Witchcraft

Participants in this study associate challenging behaviour as supernatural attributions, such as spirit possession or witchcraft. Some participants believe that the cause of the child illness is due to witchcraft and being cursed by their relatives.

“What should we do because he was bewitched as a child, they saw that he was going to make our family rich, but they made sure that they take his mind and reasoning capabilities away from him? They sometimes take him to use him, hence he sometimes doesn't return home. When we keep him locked, he hurts himself and acts aggressively by being violent and destructive, so we sometimes let him be, and when that happens, he hurts himself hard. Do you see that as being normal at all, something is honestly busy with my child?” (Participant A, female, 52yrs)

“I'm talking about people of the night, our neighbours. They are witches who go around people houses to hinder their success and progress. They never want to see us happy; they enjoy using my son, and they cursed him. Every time he is missing, we know for sure that he is right next door to us, they help us look for him knowing very well that they are laughing at us for them to use him at night. These people have cursed me since I was pregnant with him”. (Participant A female, 52yrs)

“My aunts never wanted anything good with us. They go to witchdoctors to punish us, cause us bad luck and bewitch us so that nothing good comes from us”.
(Participant F, female, 36yrs)

“They bewitched my son, after he has been diagnosed with epilepsy. This boy was very intelligent since Grade 1 to Grade 4, when he was in Grade 5, he started falling and the doctors said he got epilepsy. They were using him at night because they saw that he was intelligent, they stole his intelligence and made him be like that. Those things will go back to them.” (Participant G, female, 59yrs)

The above connotations implies that many people in rural African communities still believe that disability is caused by supernatural forces, curses and as punishment for wrongdoings or jealousy. Most of them suffer trauma and anxiety of worrying that people are out there to harm them through their children. This implies that witchcraft beliefs are linked to experiences of misfortune, rivalry and jealousy and that these beliefs can be regarded as an expression of conflict.

5.2.3.1.2. Demonic attack/Generational curses/bad luck

These reports indicate that participants believe that ancestral curses cause challenging behaviour. Some participants stated that family members deliberately sent curses or bad luck to cause mental illness among persons with intellectual disability due to family disputes. Participants are also seen to believe that unusual speech patterns associated with severe mental illness manifest demonic attacks among persons with ID.

“These people are possessed with bad spirits, curse and bad luck, they might also be bewitched or they themselves are witches who failed at a mission. (Participant T, male, 56yrs)

“These people are tormented with spirits that are really bothering them on a day to day basis, they are really suffering. I just feel sorry for them because they don't enjoy anything they are always fighting and talking in foreign languages with things in spirit.” (Participant A, female, 52yrs)

“Some of these students are sangomas and they want to hide it when they come to schools, but they really can’t hide because these behaviours will expose them. Some is due to heredity or ancestral calling; you would find that their grandmothers or even their mothers have it in the family. Some see things at night while they are going to practice witchcraft in other people’s houses, when real witches find them; they shut their mouth with intellectual disability to confuse them with demonic attacks. Other people would want to bewitch you by using other people’s children and when they find your house protected then the child would have intellectual disability because they would be cursed.” (Participant V, male, 38yrs)

Furthermore, the findings show that the participants notice that some people become mentally ill because they are gifted to take up the responsibility of healing other patients hence they get attacked as a punishment or curse of not being a traditional healer.

“This is heredity, their experiences and actions resonate that of our late grandma who used to be a sangoma. They behave like that because of their ancestral calling, they are supposed to be sangomas.” (Participant B, female, 43yrs)

“My biological father abused me as a child. He is the biological father of CC (her child); hence the child is cursed with intellectual disability. Please don’t tell anyone that I have told you this, it is our family secret. Only my parents, paternal grandmother and ZCC prophets know about this, and no one else. CC is really cursed by the ancestors because she is just a disgrace to our family and the ancestors don’t even know where they can place CC.” (Participant C, female, 26yrs)

“Funny behaviours will occur when one has ancestral calling, people will have bad luck or even curses from the ancestors. The ancestors will punish you with these behaviours when you choose not to listen to them.” (Participant M, male, 46yrs)

Participants reported that some persons with ID develop challenging behaviours because they are cursed by their significant others.

“The person who bewitched us must just stop, it’s enough. My family is possessed with bad spirits or should I say curses. I believe we got this attack when my wife

started being promiscuous, they were taking advantage of her because she was mentally unfit. The kids who are mentally sick are not mine. These children who are sick are not mine. My children are clever. The ancestors will punish you real hard if you want to play around with me. They prove to me always by giving her a sick child to show me that she was promiscuous. I cannot tell her to leave because she will suffer, her whole family is sick and my other 5 children will resent me because they really love their mother.” (Participant D, male, 58yrs)

“I was cursed by my aunts (my father’s sisters) and her children, that I will never have kids in my life. I have been in and out of hospital when I was pregnant and was also bleeding during the 9months of pregnancy. These people tide my tubes. They were jealous of my family and had too many issues with my mother. My mother died of the very same problem...intellectual disability, she was cursed and now they did the very same thing to my child. I think she might have seen things that they were trying to do to us as a child, and they tried to shut her up by giving her this mental illness.” (Participant F, female, 36yrs)

“Other causes could also myths or taboos that adults always say when you are pregnant you should avoid going to funerals and view the corpse, or going to the zoo while pregnant because the child might inherit the behaviours of those animals and also eating eggs while pregnant could lead to a child with intellectual disability. Some kids are bewitched and some is the punishment from ancestors.” (Participant O, female, 54yrs)

The demonic attack, generational curses or bad luck In these contexts, witchcraft is believed to be responsible for every social experience including, illnesses, sickness and death. The witch-figure, imbued with jealousy, is believed to derive power to harm others with witchcraft through supernatural capacity and an association with the Devil. Witchcraft seems to represent a theory of misfortune guiding the interactions between people and provides explanations, steeped in the supernatural, for almost every misfortune.

5.2.3.1.3. God's will

The findings reveal that some of these participants believe that health and illness were seen to be in God's hands. These are devoted Christians who tend to ascribe the cause of challenging behaviours of persons with ID to God's will. These comments are revealed in the following responses:

"Most of them are born like that because it is God's will and they were just naturally born like that and it is ok." (Participant N, female, 41yrs)

"At times people should just believe that others are born like that, because God created them to be like that, we just need to accept." (Participant O, female, 54yrs)

"God made them to be like that, it was only natural that they were born like that. They must go to church and get spiritual awakening because they are from God and they belong to him." (Participant W, male, 41)

The above extracts implies the salience of beliefs of intellectual disability (naturalistic or religious) largely determines that challenging behaviour in situations of high uncertainty or imminent danger, religious attributions are more likely to be made. Attributions are made to help people maintain their sense of control and meaning (Pargament & Hahn 1986). They believe that challenging behaviour misfortunes, transcendence would be achieved by a belief such as God is in absolute control and He has a bigger plan with their life. The beliefs and attributions help people to cope with anxiety and create meaning.

5.2.3.2. Bio-medical factors

Most participants reported that biomedical factors can cause challenging behaviour among persons with ID.

5.2.3.2.1. Heredity/ genetic conditions

Many participants reported that they believe challenging behaviours among persons with ID to be hereditary. For example,

“This is heredity from my grandmother who birthed my father, and also my young aunt (my father’s last-born sibling). It could only be a biological factor that created this intellectual disability because of heredity. (Participant E, female, 40yrs)

“They inherited this from their family gene because sometimes four kids of the same parents would have intellectual disability. At times it is the child/children together with their mother would have the same condition.” (Participant N, female, 41yrs)

“This people are like this because of the medical conditions, they are sick and mentally challenged. Complications at birth and genetic conditions or heredity that would cause this people to have intellectual disability and they would show challenging behaviours.” (Participant U, female, 36yrs)

Furthermore, some participants indicated that traditional healers describe what they believe is a genetic predisposition to challenging behaviour as ancestral calling/*gothwasa*. This is when ancestral calling is passed from one generation to another, from the one generation in the past to another generation in the present and possibly to another person in the future in the same family.

“This is heredity, their experiences and actions resonate that of our late grandma who used to be a sangoma. They behave like that because of their ancestral calling; they are supposed to be sangomas.” (Participant B, female, 43yrs)

“People must follow their own traditions, most of them know that they have these things in their family’s cultural background or you would find they are just chosen in their family to become traditional healers but they choose to ignore it. They need sangomas to assist them to connect with their ancestors through initiation ceremonies to help prepare them to become traditional healers.” (Participant M, male, 46yrs)

The above extracts expresses heredity as the passing on of physical or mental characteristics genetically from one generation to another or particular the tendency of offspring to resemble parents or ancestors through such transmission. They develop comfort and well-being in connecting with their late relatives through rituals.

5.2.3.2.2. Problems during pregnancy

The study revealed that the use of alcohol or drugs by the pregnant mothers can cause intellectual disability. In fact, alcohol and smoking during pregnancy is known to be the leading preventable cause of intellectual disability. Other risks include malnutrition and illnesses of the mother during pregnancy. Others believe that supernatural causes such as witchcraft and curses caused by others could harm or take the fetus intellect. The above is revealed in extracts below:

“I was also young 17 years of age and we were poor. I drank a lot of harmful things when I was pregnant so that the baby can die. I hated that pregnancy because I was not even eating healthy.” (Participant C, female, 43yrs)

“Some irresponsible mothers smoke and drink during pregnancy. Some would also be in and out of hospital during pregnancy because they not taking care of themselves hence they are always ill during that time” (Participant N, female, 41yrs)

“It can be caused by witchcraft or a curse, what the child might have been exposed to while growing because it is believed that witches can look into the future of the child (if the child will upgrade the family) and steal his intellect. (Participant R, female, 52yrs)

The above extracts indicate the trauma of being pregnant as a young person can lead to excessive drinking or the intake of harmful objects to harm the unborn child. The fear of being pregnant would also results in punishing of self or foetus by not eating healthy or not eating at all.

5.2.3.2.3. Problems during childbirth and after childbirth

The participants indicated that problems at birth such as prematurity and low birth weight predict serious problems more often. They also suggested that difficulties in the birth process such as temporary oxygen deprivation or birth injurie may cause intellectual disability.

“Other kids were born before their time, born too small and possibilities are the brain hasn’t fully developed” (Participant U, female, 36yrs)

“Some fell with their head after an accident which could cause a child to have intellectual disability. When delivering, a child can fall with their head because some mothers can deliver their new-born while standing”. (Participant Q, female, 47yrs)

“Difficulties in breathing when they were born and other biological factors could also affect their mind.” (Participant N, female, 41yrs)

The study further revealed that there could also be problems after birth, such as childhood diseases that can cause irreparable damage to the brain and nervous system.

“Not forgetting the medical conditions a child could inherit while growing up e.g. epilepsy, measles, polios and other things because those can damage the brain. A person can also get epilepsy after an accident.” (Participant W, male, 41yrs)

“Learning disability also falls under intellectual disability because they are not on the same intellectual average as peers. Some did not develop at the same time with peers, their IQs would be low and they could be identified in schools or even pre-schools.” (Participant Q, female, 47yrs)

5.2.3.3. Psychosocial factors

5.2.3.3.1. Stress

The below extracts explain that most parents of persons with intellectual disability experience physical and mental stress.

“Nobody understands what I am going through, out of twelve children, seven of them have the so-called intellectual disability, and the doctors say that their mother also has it...I have no hope, I don’t even know if these children are really mine.”
(Participant D, male, 58yrs)

“I was in a lot of stress and tried to commit suicide a couple of times during my pregnancy. I had no hope and support at all. I got even worse when I gave birth to a child with ID, that situation was too overwhelming for me, I was not coping. The situation was just too much for me to bare.” (Participant E, female, 40yrs)

“Eish... I really don't want to lie; I did not want to have this child. I knew I have failed and people were going to laugh at me, especially my in-laws and my jealous friends. I couldn't hold my child for a week or two after giving birth, I was really stressed.” (Participant J, female 56yrs)

“Too much stress when the mother is pregnant because some fathers leave them stranded without giving them proper emotional and financial support.” (Participant O, female, 54yrs)

“Most mothers feel neglected and some cannot handle the hardships of having children with intellectual disability. Some also suffer a lot of stress because they get embarrassed with the way neighbours look at them for having children with ID” (Participant M, male, 46yrs)

The above extracts points out that parent mainly mothers tend to isolate themselves because of feelings of shame, embarrassment and guilt. Participants explained that their first reaction to the birth of a child with an intellectual disability was a combination of hopelessness, loss and resentment. These feelings can also be an obstacle for the parents' capacity to accept the child. Participants also indicated that extended stress leads to depression and burnout (which results in its own consequences socially, psychologically/emotionally, and physically) appear to be the main consequences of having a child with ID or being alone with no support during pregnancy. These consequences are caused by several factors, particularly poor socio-economic conditions which often cause lot of stress. Lack of support from family/friends or the community, and the stigma attached to disability in the township.

5.2.3.3.2. Abuse/Family conflicts

Abuse and family struggles is illustrated below:

“My biological father abused me as a child. He is the biological father my child, hence the child is cursed with intellectual disability. Please don’t tell anyone that I have told you this, it is our family secret. Only my parents, paternal grandmother and ZCC prophets know about this, and no one else. CC is really cursed by the ancestors because she is just a disgrace to our family and the ancestors don’t even know where they can place CC.” (Participant C, female, 26yrs)

The stress and physical abuse I got from my husband could also be a cause to this child. I fell on my stomach several times when I was pregnant, because when my husband gets too drunk, he behaves aggressively. I just thought maybe the stress, abuse and the child falling, might have caused complications to the child.” (Participant E, female, 40yrs)

“Some mothers could be physical, psychologically or emotionally abused when pregnant and can produce a child with intellectual disability. Many students in this school come from a lot of dysfunctional or abusive families, you can even see with the way they talk that they speak from a place of a lot of pain.” (Participant N, female, 41yrs)

“They also learned fighting from their parents when they fight from home. Families that usually lacks order create a very difficult environment for people to grow and develop in” (Participant Q, female, 47yrs)

The study revealed that abuse in the family can be characterised by a person, particularly fathers subjecting or exposing mothers or their children to behaviour that may result in psychological trauma, including anxiety. They also indicate that emotional abuse is another form of abuse often associated with situations of power imbalance in abusive relationships which results in children to have behavioural problems such as bullying and conducting violence.

5.2.3.3.3. Death

The trauma of losing a loved one through death while expecting can act in much the same way as stressors.

“My stresses while pregnant affected my unborn child. I suffered too much stress when I lost the father of my child while pregnant. I didn’t know what to do, I was depressed and had suicidal ideas when I was pregnant. I didn’t have anyone at that time because my mother had passed away the beginning of that particular year and my father was never there. Me and my siblings were just scattered around, and we never really had a relationship.” (Participant J, female, 56yrs)

“Some of these children lost their fathers when the mothers were still pregnant with them. One needs to understand that when pregnancy and grief take place at the same time, hormonal changes may have more extreme effects on the unborn child causing them to have intellectual disability.” (Participant R, female, 52yrs)

The study discovered that these stressors can trigger physical symptoms that may affect pregnancy. When pregnancy and grief take place at the same time, hormonal changes may have more extreme effects on the unborn child. Health complications for the mother or child during pregnancy can affect physical symptoms that could impact on the unborn child. The foetus can be susceptible to these changes. Some participants suggest that stress during pregnancy could cause developmental delays resulting in having a child with ID. In extreme cases, these effects may impact the child’s life later.

5.2.3.4. Socio-economic factors

5.2.3.4.1. Poverty (Lack of education and Unemployment)

The participants’ experience of poverty, unemployment and education seems to be associated with poorer parenting practices. Their experience of poverty is likely to affect their children with intellectual disability with poor child health and well-being. This is revealed in the responses below:

“I don’t even have a job because I don’t have high school, I used to do people’s laundries and clean houses, my bosses moved. I sometimes fail to get medication for my child or take him to check up because we don’t have transport money”

“How can we succeed or help this child? I don’t even have any money, the father of this child ran away”

“These behaviours will never change; they will always increase because no one takes care of us. We are staying far away from the hospital and our village has few taxis. I don’t even have money to take care of this child, we use grants money to pay for schools fees and transport, there is no money left for food.” (Participant L, female, 31yrs)

“Raising a child in poverty conditions can also cause an illness, some conditions are just too difficult to keep the child healthy. Some parents are not employed and are dependent on the grant of their children.” (Participant N, female, 41yrs)

“Most of them come from families where education is not even taken seriously, poor living arrangements and lack of basic needs” (Participant Q, female, 47yrs)

Low socioeconomic levels were correlated with higher cognitive disturbances, depression, anxiety, and despair in parents. Their children need hospitalisation, medical care and basic care giving services beyond those of normal children. Participants indicated that these demands can be prolonged as they cannot cope with the financial demands for the children’ needs.

5.2.3. Theme 3: Interventions to cope with challenging behaviour

The participants in this study relied on three strategies to cope with challenging behaviour of persons with ID, religious coping, traditional methods of coping and reliable influences (Healthcare staff, community, family, and government support).

5.2.4.1. Religious methods of coping (Christianity)

This study discovered participants reliant on the church, including prayer and other ritualistic practices recommended by the church. The participants revealed that the western medicine together with rituals recommended by the church will assist the children

to cope better with challenging behaviours. Participants clearly stated that they go to ZCC and Pentecostal church to get help from their priests. The illustrations below state how church connection is important to most of the participants.

“I am a believer and I pray harder and I know that one day my child will be healed by God. Our pastor always prays for her and when she has episodes of demonic attacks, I run to the pastor’s house so that he can come and assist us. I believe that one day through prayer and faith that what has happened to my child will never ever happen again. He will be fine for good.” (Participant F, female, 36yrs)

“I would always go to church every Sunday and during our church meetings. I have always believed in the doctrines of our church. Our prophets are always there to assist during our bad luck times. When I was pregnant, they really helped me a lot to cope with my situation because it was not easy for me to cope. But the Zion Christian church really helped me cope.” (Participant C, female, 26yrs)

“We go to ZCC, and the priests give us tea, salt and water that we use from the church to our home, it helps remove the bad spirits and anything to do with witchcraft.” (Participant D, male, 58yrs)

“My boyfriend keeps on inviting pastors to our house, introducing us to many churches seeking for help and healing.” (Participant H, female, 41yrs)

“Our pastor is always praying for my child. The government should also take initiative of going to families that are poor and have children with intellectual disability by helping them financially so that they can take care of these children.” (Participant L, female, 31yrs)

“These children are sick they should just rely on regular hospital check-ups for medicines, they should also believe that it is by the will of God because if we don’t we will end up accusing wrong people.” (Participant U, female, 36yrs)

Based on the above responses, most participants rely on their religiosity is interesting in that they discussed that they had always been religious and surely devoted to ZCC church. The participants also discussed their reliance on the ZCC and other Pentecostal

church, particularly the church practices (tea, salts and rituals) that the church priests and elders make for sick people. The instructions they get from the church really help the persons with ID to deal with challenging behaviour.

5.2.4.2. Traditional methods of copying

Participants understood intellectual disability and challenging behaviour to be mainly caused by supernatural agents, such as witchcraft, and are thus to be treatable with traditional medicines. Sacred or ancestral healing, on the other, may include rituals performed by spiritual healers especially to those who they believe have the powers to be traditional healers. The following extract illustrates this point:

“I always take them to traditional healers so that they can help them because the doctors just help with medication, they cannot do anything besides that. They can’t even see what wrong with them. But my advisors, the sangomas are always helping her and the children.” (Participant D, male, 58yrs)

“Witchcraft is there, and it exists. People always take care of themselves. I believe in traditional healers because they know how to remove these things.” (Participant G, female, 59yrs)

“I believe in traditional healing, I grew up believing that. I was taught that every time I get emotionally or physically confused, I should go to sangomas” (Participant H, female, 41yrs)

“A child should be protected by either a traditional healers or pastors when they are born. These things are real.” (Participant I, female, 44yrs)

“Traditional healers make life easier for us, I suffered tremendous stress and only found hope and peace from traditional healers. I don’t dispute medicine, but I just wish that doctors and priests could learn what traditional healers do and work together to help assist people.” (Participant J, female, 56yrs)

“People should always take care of themselves because people or friends could easily want to hurt them by sending evil spells of witchcraft on them. I believe in

traditional healers because they know how to remove these things.” (Participant K, female, 37yrs)

“People must follow their own traditions, most of them know that they have these things in their family’s cultural background or you would find they are just chosen in their family to become traditional healers but they choose to ignore it.” (Participant M, male, 46yrs)

“They need sangomas to assist them to connect with their ancestors through initiation ceremonies to help prepare them to become traditional healers.” (Participant T, male, 56yrs)

The study also revealed participants belief of traditional ceremony that should be conducted to connect persons with intellectual disability with their ancestors regarding their illness. They emphasised that this is a crucial element in their clan because it serves to connect both the living and the dead in the entire clan. They also revealed that when anything significant happens in their family or the entire clan the ancestors or spirits must be notified about it through the spilling of blood of an animal. Some mentioned that this has been the practice in their family for many years whenever anything of significance happens.

“My son always looks rejuvenated and free after a sangoma’s visit. He looks properly revitalised because of the muti pouch made of crystals they gave from the sangoma. That muti pouch really helped him a lot because it sets him grounded. (Participant A, female, 52)

“We are making arrangements for them to start with the initiation. The sangomas told us to conduct a traditional ceremony for the boys to request help from my family ancestors. They told us that they will be pleased because they would be notified about the boys, and that everything will run smooth.” (Participant B, female 43)

“We always connect with the ancestors whenever something new happens in the family. I traditional ceremony will be made where the entire clan attend. The family

traditional doctor and the elders will take charge of everything. A goat will be slaughtered for the family spirits.” (Participant G, female 59yrs)

The study also revealed that Africans have abandoned their traditional ways of living and methods healing.

“Africans don’t talk about our African/cultural ways of doing things, white people take these things from us, then interpret them differently and categorise them in their own knowledge.” (Participant H, female, 41yrs)

“We took white people’ healing too much, they cannot even see what we are struggling with. We ran away from our traditions. Eurocentric healings are failing us because they don’t understand what we go through, they are not familiar with what we deal with daily. We must follow our roots. This intellectual disability is too much in our culture now because we ran away from our culture. We need to go back to our African ways of healing.” (Participant S, female, 39yrs)

This study revealed an interesting observation regarding participants with strong cultural devotion to their traditional remedies, which follows their belief in the African indigenous way of practice. Participants also stated that their trust and hope in traditional methods and ancestral ceremonies to initiate their children helping them cope better with challenging behaviour. Other participants mentioned that they believe and rely on the traditional doctors for many things in their lives. They further indicated that even when they get medication from the hospital and teas from ZCC church, they will never stop consulting with the *sangomas* because they know how to deal with bad spirits and healing.

5.2.4.3. Reliable influences (Healthcare staff, community support, family support, and government support)

5.2.4.3.1 Family and Friends support

Participants also stated that they depend heavily on the support they receive from their family and friends. The following extract illustrates this aspect:

“My uncles and sibling are always available to assist whenever my son portrays challenging behaviour, even when I’m not available for work, they would take him to our sangoma. My friends pray for us and show us tremendous support especially when I’m down and confused, they provide me with strength.”

(Participant B, female, 43yrs)

“My friends contribute a lot in helping me deal my child. I don’t know where I would have been if my friends were not here to assist. I have no-one from my family to support me because they are embarrassed with my child’s condition.”

(Participant C, female, 26yrs)

The support they receive when their children’s condition accelerates, as well as the follow-ups and prayers they get from friends, offer them comfort and emotional support.

5.2.4.3.2. Health Care and Family Support

The study reported that participants also trust on the support of their children and the healthcare staff. He discussed that the support he receives from his children as well as the constant follow-ups and treatment he always come to get from Polokwane hospital offer him comfort and emotional support.

“What can I do without my children who are not sick, the two are working and they always assist financially and emotionally to their mother and sick siblings. They always take others to school and hospital while others can help others who are home. The medication we take from the hospital also helps sometimes.”

(Participant D, male, 58yrs)

“I am just happy to have my family that always assist me with my son and also accompany me to the hospital for his regular check-ups.”

“They need to get quarterly checked by health professionals, pastors and traditional healers to be able to cope with their condition. They should collaborate, if these people are always at special schools for these children, believe me they will start functioning well.”

(Participant N, female, 41yrs)

“Health professionals (psychologists, social workers and nurses), pastors and traditional healers should work together for person with intellectual disability to cope with their challenging behaviours.” (Participant Q, female, 47yrs)

The findings also show that participants believe that the combination of medical health care support, family support, traditional methods and religious methods giving them courage and hopefulness to better help and care for persons with ID to cope better with challenging behaviour.

5.2.4.3.3. Health Care Support/Educational support

Participants also reported that they also thankful for the support they receive from the healthcare staff and teachers at special schools. Some mentioned that they are helping them raise their children to become better individuals in the future.

“I can never thank enough the support I get from the nurses and teachers, I don’t know where I would be without them, they assist me to raise my daughter, and I will always be forever proud and grateful.” (Participant E, female, 40yrs)

“They need proper medical help; they need to take their medication regularly and they need facilities from that government that will help them in terms of training to become better human being in the future.” (Participant P, female, 41yrs)

“When health care staff and teachers work well together, a lot of improvements will be visible on these children.” (Participant U, female, 36yrs)

Parents rely mostly on Health care support and educational support for their children’s stability to cope with intellectual disability.

5.2.4.3.4. Healthcare staff, community, family, and government support

Others clearly states that they find medical health care and government support helpful to better manage challenging behaviour of persons with ID. This study also revealed that most participants agree that a holistic care support from all stakeholders would help persons with ID to better manage challenging behaviour.

"I appreciate the tremendous support I receive from my neighbours and nurses from Boyne clinic whom I attend church with, they always show care and love to my son by checking up on us." (Participant F, female, 36yrs)

"Health professionals (psychologists, social workers and nurses), pastors and traditional healers should work together for person with intellectual disability to cope with their challenging behaviours." (Participant Q, female, 41yrs)

"They must go to church and get spiritual awakening because they are from God and they belong to him. It is just by the will of God. Pastors should also be available at schools for those who need religious interventions and healing." (Participant T, male, 56yrs)

"The government should always support this children, medication, psychologists, nurses and doctors must always be available in schools. Traditional healers and priests need to also be available at schools for the services they would provide for those who believe in traditional methods." I find it unfair that only teachers need to deal with these very hard behaviours alone daily." (Participant W, male, 41yrs)

This study also revealed that most participants agree that a holistic care support from all stakeholders would help persons with ID to better manage challenging behaviour.

5.3. PART C: THE PSYCHOLOGICAL INTERPRETATIONS OF THE THEMES

5.3.1. Understanding challenging behaviour

Challenging behaviour in this study was understood as behaviours that are fearful, traumatic, unusual and confusing to understand. Hallucinations were also discovered as challenging behaviours that are frightening, whereby they had experienced their children/leaners seeing, hearing or feeling things that don't exist outside their mind. Aggressiveness was witnessed to being stimulated by episodes of anger, violence and irritability among persons with ID. It was also witnessed that aggressiveness is their way of coping with uncomfortable situations around them. They would scream, yell, shout or fight to express their unhappiness or discomfort. They would also self-injure when they

feel they are not listened to, they have been told off or they have little or no choice about things. This was understood as their way of indicating their needs and feelings.

Some forms of these challenging behaviours were viewed as repetitive behaviours. A person with ID might be finding a task too difficult or overwhelming hence they resort to annoying behaviour assisting them to escape from what is expected from them or a routine that keeps them calmer. They were seen finding it difficult to control their sexual desires and this in turn resulted in some being abused by their family members or elders in the village, taking advantage of their intellectual disability. They also struggle to care for self. It has also emerged from the results of the study that persons with profound and severe levels of ID will struggle to care for themselves because of their inability to lead a fully independent life due to challenges communicating, taking care of themselves, or interacting with others.

It was revealed that when an individual in their culture has an ancestral calling, he/she sometimes presents with symptoms and signs that are like those of a person with a mental illness/psychosis. This reveals that there are feelings of paranoia between extended family members because there is lack of trust between them. They have this strong belief that others will harm, deceive, take advantage or kill them because of jealousy.

5.3.2. Causal explanations of challenging behaviour

This study demonstrated varied beliefs about causal explanations of the challenging behaviour. Beliefs about the causes of challenging behaviour often included a mix of both western (biomedical) and cultural factors. Supernatural factors such as witchcraft, generational curses or badluck and God's will were reflected as cultural health attributions, beliefs, and practices. Witchcraft was regarded as a notion of misfortune guiding the interactions between people and provide explanations, steeped in the supernatural, for almost every misfortune. It is witnessed that many people in rural African communities believe that disability is caused by supernatural forces, curses and as punishment for wrongdoings or jealousy. Most of them suffer trauma and anxiety of worrying that people are out there to harm them.

God's will implied that challenging behaviour misfortunes was a confirmation of a belief that God is in absolute control and He has a bigger plan with their life. The study discovered "higher power" beliefs and attributions that helped people to cope with anxiety and create meaning of their life.

It was expressed in this study that bio-medical factors such as heredity or genetic conditions, problems during pregnancy, childbirth and after childbirth are usually the leading cause of challenging behaviour among persons with ID. The study revealed that the trauma faced by young persons with unplanned pregnancies has lead to excessive drinking and use of drugs. The anxiety and distress of being unwillingly pregnant was seen as punishing of self or foetus by not eating healthy or not eating at all. It was also discovered that difficulties in birth processes may cause intellectual disability.

Psychosocial factors such as stress, abuse, family conflicts and death were also confirmed to may have more extreme effects on the unborn child. The study revealed that abuse in the family can be characterised by a person, particularly fathers subjecting or exposing mothers or their children to behaviour that may result in psychological trauma, including anxiety. They also indicated emotional abuse as another form of abuse often associated with situations of power imbalance in abusive relationships which resulted in children having behavioural problems such as bullying and conducting violence.

This study also revealed that the trauma of losing a loved one through death while expecting could act in much the same way as stressors. It was explained that when pregnancy and grief take place at the same time, hormonal changes may occur. It was also confirmed that being alone with no support during pregnancy or extended stress leads to depression and burnout which could appear to be the consequence of having a child with ID.

The study also revealed that mothers have a tendency of isolating themselves because of feelings of shame, embarrassment and guilt. Others have explained that their reaction to the birth of a child with an intellectual disability was a mixture of hopelessness, loss and resentment. These feelings can also be an obstacle for the parents' capacity to accept the child.

Socio-economic factors such as poverty, lack of education and unemployment because low socioeconomic levels were correlated with higher cognitive disturbances such as depression, anxiety, and hopelessness in parents. Their children need hospitalisation, medical care and basic care giving services beyond those of normal children.

5.3.3. Copying with challenging behaviour

Above all, the participants in this study relied on three strategies to cope with challenging behaviour of persons with ID, religious coping, traditional methods of coping and reliable influences (Healthcare staff, community, family, and government support). This study discovered participants reliant on the ZCC and Pentecostal church, including prayer and other ritualistic practices (tea, salts and rituals) recommended that the church priests and elders make for sick people. Their beliefs and devotion to their church practices were proved to have been important to most of the participants. The participants revealed that the western medicine together with rituals recommended by the church will assist the children to cope better with challenging behaviours. Their beliefs in the instructions they get from the church helped the children to cope and also deal with challenging behaviour.

The study also discovered that most participants understood intellectual disability and challenging behaviour to be mainly caused by supernatural agents, such as witchcraft, and are thus to be treatable with traditional medicines. This study revealed an interesting observation regarding participants with strong cultural devotion to their traditional remedies, which follows their strong belief in the African indigenous way of practice. Their comfort, trust and hope in traditional methods and ancestral ceremonies to initiate their children helped them cope better with challenging behaviour.

Participants relied on the comfort of dedicated influences such as healthcare staff, community support, family members, and spirituality or higher power. The study revealed that participants gained strength and confidence through the support of others. For families where mothers also had ID, it was indicated that the most significant emotional and physical support was received from the father and siblings of person with challenging disabilities. This support seemed to provide a sense of comfort and reassurance in their time of uncertainty when challenging behaviours occur. This study revealed that a holistic

care support from all stakeholders, the government, the healthcare staff, family, religious and traditional support helpful to better manage challenging behaviour of persons with ID.

5.4. Concluding remarks

This chapter presented the results of the study. The findings of this study show that in general, this study has found complex concepts regarding challenging behaviour. It further shows that challenging behaviours are behaviours that are not easily managed. Several causal explanations of challenging behaviour frequently included cultural/religious/spiritual beliefs, myths and explanations were presented. Fewer participants mentioned western (biomedical) explanation as the cause of the challenging behaviour. However, this suggested a strong belief of a holistic approach and trusting approach to treatment for most participants in this study. The psychological interpretation of the findings was also outlined. The next chapter discusses the model discovered by the study.

CHAPTER 6

DEVELOPMENT OF AN EXPLANATORY MODEL

6.1. Introduction

This section describes the conceptualised model developed based on the findings of the study. This model identified the influence of culture on challenging behaviour, thus making it important to collaborate cultural contexts with the biological, psychological and social mental health care to understand challenging behaviour as well as to design and deliver appropriate mental health care interventions. The participants in the study were parents and teachers of persons with intellectual disability who showed signs of challenging behaviours. All the participants in this study came from different rural areas within the Capricorn district of Limpopo Province. All participants were able to explain their notions of challenging behaviour.

6.2. Procedure in theory building

The researcher in the present study was guided by Wacker's procedure in theory building (Walker, 1998). The theory guided the researcher to develop and articulate an explanatory model on challenging behaviour in persons with intellectual disabilities based on the views of parents and teachers who participated in the study.

A general procedure for theory-building and the empirical support for the theory

	Purpose of this step	Common question	'Good' theory virtues emphasized
Definitions of variables	Defines who and what is being included and what is specifically excluded in the definition?	Who? What?	Uniqueness, conservation
Limiting the domain	Observes and limits the conditions by when the antecedent event and where the subsequent event is expected to occur.	When? Where?	Generalizability
Relationship model Building	Logically assembles the reasoning for each relationship for internal consistency.	Why? How?	Parsimony, fecundity, internal consistency, Abstractness
Theory predictions and empirical support	Gives specific predictions. Important for setting conditions where theory predicts. Tests model by criteria to give empirical verification for the theory. The riskiness of the test is an important consideration.	Could the event occur? Should the event occur? Would the event occur?	Empirical tests Refutability

Table 3 Outlines the general procedures for developing theory. J.G. Wacker. *Journal of Operations Management* 16 (1998) 368

According to Wacker (1998), a good general procedure in theory-building should aim to answer the "... questions of who, what, when, where, why, how, should, could and would" (p.368). To address these questions, Wacker (1998) suggests that theory-building should be under the following four procedures that the researcher also followed in the present study:

6.2.1. Definitions of variable: This refers to variables of challenging behaviour that have emerged from the views of parents and teachers of persons with intellectual disabilities. Through different narrations, participants understood, described and associated challenging behaviours as culturally constructed behaviours that include possession of evil spirits, having ancestral callings, demonic attack, involuntary movements or spirits moving in the body, mental illness, hallucinations, and unusual behaviours. They also described challenging behaviours as socially constructed in that for behaviour to be considered challenging; teachers and parents interpreted it as being, dangerous, frightening and stressful.

Examples of such socially constructed behaviour were found to include: aggressiveness, self-injurious behaviours, stereotypical behaviours, inappropriate sexual behaviours, confusion and inability to care for oneself. Biomedical explanations were also given to explain challenging behaviour. Such biomedical reasons included the following; infections (present at birth or occurring after birth), chromosomal abnormalities (such as Down syndrome), metabolic (such as hyperbilirubinemia, or very high bilirubin levels in babies), toxic (intrauterine exposure to alcohol, cocaine, amphetamines, and other drugs), trauma (before and after birth), nutritional (such as malnutrition) and also unexplained (doctors do not know the reason for the person's intellectual disability). The study further found that the management of challenging behaviour requires holistic management approaches. Such holistic management should involve the collaboration of a wide range of stakeholders that include healthcare professionals, psychology professionals, traditional healers, religious healers, families, and non-governmental organisations.

Based on the above findings, it can be suggested that cultural, psychosocial and biomedical factors play a critical role in determining what is understood and perceived as challenging behaviour. It was also evident from the findings of the study that challenging behaviour requires holistic management that entails the participation of different role players. Similarly, the study also revealed that holistic management approaches for challenging behaviour of persons with intellectual disabilities needs to be implemented.

6.2.2. Limiting the domain: This means when and where these challenging behaviours occur. The participants explained that challenging behaviours occur when an individual is spiritual? In some instances, this may be shown when such individual transits beyond their own body into the realm of ancestors. For instance, this may happen when they are having awareness outside of themselves and would usually have convulsions or when they are hallucinating. Other participants also suggested that challenging behaviours can be reflected in involuntary movements on the part of the affected person and when they are out of consciousness or out of touch with reality. Some participants explained that when some are not feeling well or lacking medication, they would show this challenging behaviour. Some participants mentioned that this challenging behaviour occurs when an individual is experiencing demonic attacks. Evidence from the interviews clearly

demonstrated how parents indicated that they understood what their children' spirit wanted during those times when the behaviours would occur, meaning someone who possesses spiritual entity in their body.

6.2.3. Relationship (model) building: The general procedure for a good-theory building to answer the questions of why and how does the challenging behaviour happen. Participants in this study tend to perceive challenging behaviour as caused by witchcraft, curses, bad luck and punishment from God or the ancestors. They also believe that medical conditions caused by biological factors (genes, down syndrome, foetal alcohol syndrome), psychological factors (traumatic, abusive and stressful life events) and environmental factors.

Another important variable closely related to the meaning that the participants ascribed to their experience of living with persons with intellectual disability and understanding their challenging behaviour is that most of the participants in the study believe in traditional healing. Some were members of the ZCC and believed in the doctrines of their church. The participants described the cause of challenging behaviour to some kind of higher power.

The participants in this study relied on a few strategies to cope with their children' challenging behaviour. These coping strategies included religious practices and consultation with western-trained health practitioners. In some cases, the participants chose to consult traditional healers whilst others sought support from family, non-governmental organisations (NGOs) and the broader community.

6.2.4. Theory predictions and empirical support: Based on the above descriptions that were according to Wacker's model of theory building, it does appear reasonable to make some predictions of challenging behaviour as understood and perceived by the participants in the present study. The explanatory model presented in the section below is thus based on theory building exercise.

6.3. Toward a culturally informed explanatory model for challenging behaviour

The following explanatory model for challenging behaviour is proposed:

The Bio-Psycho-Socio-Cultural Model (BPS-C) for Challenging Behaviour

Internal Factors

Biological factors

- Heredity/genetic
- Neurological disorders (epilepsy, TBI, strokes)
- Immature brain development (Unusual behaviour, Involuntary movements)

Psychological factors

- Classification of ID

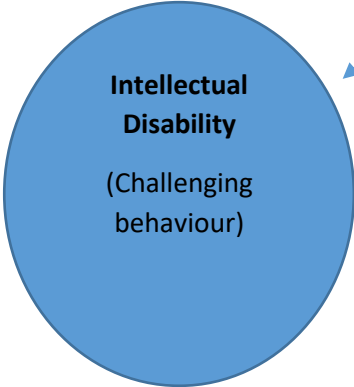
External Factors

Cultural factors

- Witchcraft /evil spirits
- Ancestral calling
- God’s will

Social factors

- Socio-economic factors
- Environmental factors
- Prejudice/Discrimination



Intervention

- Spiritual (Traditional/Religious methods)
- Reliable Influences (Mental healthcare staff, community, family)

Figure 3: Bio-Psycho-Socio-Cultural Model (BPS-C)

6.4. Description of the model

6.4.1. Major concepts of the model

The model integrates components of the Bio-Psycho-Social and cultural aspects to understand and explain challenging behaviour. The two components are the main idea that explains the model.

a) Internal factors

The Bio-psychosocial approach was used in this model to understand the challenging behaviour conditions reflected by persons with intellectual disabilities. Bio-psychosocial approach posits that biological, psychological, and social factors play a significant role in disease causation and treatment. This study describes the internal factors as biological factors that include genetic predisposition, problems during pregnancy, problems during or after childbirth which could result in immature brain developments or neurological disorders. Internal factors also include psychological factors which are the classification of ID which ensures that they are not overemphasized as the defining factor of a person's overall ability, without adequately considering functioning levels.

b) External Factors

The external factors are psychological or behavioural (lifestyles, health beliefs), and social factors (family relationships, socioeconomic status, social support, environmental) in the explanation of path challenging behaviour. The bio-psycho social theory explains that all the three domains play an equal part in the manifestation of all the health situations, and that none of them may be used in isolation to explain any patient or pathology with the exclusion of the other two. However, this study discovered external factors that advanced the model. These factors allude to a number of cultural practices that were identified by a large number of the participants in the study whom were devoted to the cultural understanding of the causes of challenging behaviour. Some mentioned that they believe the disease is caused ancestral calling inherited from the history of the family, others believe it is caused by witchcraft, bad luck, misfortunes or God's will. It is for this reason that this model advances the bio-psychosocial view by taking into account the individual's

bio-psycho-social and cultural experiences because the cultural factor adds to the holistic perspective.

c) Interventions to cope

The concept of this model provides a useful holistic framework for collaboration of clinicians, traditional healers, religious healers and family and community support to provide culturally relevant care of challenging behaviour for persons with intellectual disabilities. This model call for the involvement of all stakeholders because of the multifaceted nature of challenging behaviour as it is the result of the biopsychosocial and cultural factors. When applied to illness beliefs, the beliefs and attitudes from a particular cultural group's worldview or cultural model of disease influence perceptions about the meaning of an illness, the types of treatment or remedies that are useful, and the likely outcome of health behaviours related to the prevention and control of disease.

6.4.2. Sub-concepts of the model

Sub-concepts are categorized as biological, psychological, social and cultural personal factors. These factors are predictive of a given behaviour and, are shaped by the nature of the target behaviour being considered.

a) Heredity

In this study heredity refers to the biological inheritance from either parents or bloodline relatives. As reflected in the results section, some of the participants were of the view that ID is a result of inheritance from some members of the family.

b) Neurological disorders

The results stipulated that participants believe that the brain infection might have been present at birth or occurring after birth will source biological factors that contribute to epilepsy, traumatic brain injuries or strokes.

c) Immature brain development

Participants in these study specified that problems during pregnancy, child birth or after child birth can affect the brain development of a child and thus lead to immature brain development

d) Classification of ID

The nature of challenging behaviour is also based on the behavioural sequel which is aligned on how intellectual disability was classified on the four categories, mild, moderate, severe and profound. This means that the most severe would also show the most challenging behaviours.

Participants in these study specified visibility in unusual behaviour and also involuntary movements as prove for delayed developmental milestones from an earlier age such as lack or slow development in motor skills, language skills, self-help skills, etc. especially when compared to peers.

e) Witchcraft or evil spirits

The participants believed that confusion, screaming, aggressive behaviour, inappropriate sexual behaviours, stereotypical behaviour, etc. are caused by witchcraft or demonic attacks. They illustrated that these challenging behaviours are usually visible when a child is possessed with evil spirits. They believe that the child would be cursed by friends, relatives or neighbours because they are jealous of them and might have also seen the child' bright future and destroys it through witchcraft.

f) Ancestral calling

The participants believed that hallucinations (speaking using unfamiliar languages, hearing voices and habitually in and out of touch with reality) usually occurs when they believe that a child has supernatural powers to become a *sangoma*. Participants also believed that a child could also inherit ancestral calling or traditional healing from their family history of ancestral beliefs.

g) Gods' Will

The faith that Christian participants have upon believing that the cause of their child or learners' illness may be the will of God.

h) Socio-economic factors

These factors include poverty, malnutrition, unemployment and lack of education. The results proved that children growing up in poverty are at a higher risk of malnutrition, and those with intellectual disability are likely to get worse in poverty situations. The results section also stipulated that lack of parents' educational background and unemployment resulted in them not being able to handle the special child' needs or even taking better care of them.

i) Environmental factors

Environmental factors such as trauma, stress and abuse of mothers while pregnant inclusive of the maternal use of toxic things like alcohol, cigarettes or cocaine could affect the brain development of the foetus. Participants illustrated that some students come from dysfunctional or abusive families, and they also learned fighting from home creating a very difficult environment for persons with ID to grow and develop in.

j) Prejudice/Discrimination

The study demonstrated that persons with intellectual disability are rudely mistreated by others and even in their families. One participant in the study believed that children with intellectual disability were not his own but were conceived as a result of promiscuity. Some teachers also explained how other teachers mistreat or mock them.

k) Traditional/ Religious methods of copying

Traditional methods are usually used by participants with strong beliefs in traditional remedies, cultural rituals and practice.

Religious methods are used by Christian participants who are devoted to their church beliefs and their methods of healing (prayers, faith in God and also instructions from church).

1) Reliable Influences

The study explained that those who understand mental, medical and genetic condition rely heavily on the mental healthcare support they receive from psychologist and nurses. They believe it is enough to treat the person who has an intellectual disability. The support they receive from other family and community members. Their interventions to resolve problems e.g. hunger assists to reduce poverty, their emotional support and at times being assisting them when they cannot cope with challenging behaviour.

6.5. The cultural element in challenging behaviour

Amid existing challenging behaviour models, this advanced model is bringing the missing links of the cultural aspects to define challenging behaviour in an African setting. This model would deal with the premise that knowledge, even if it is scientific knowledge emanates from a cultural foundation or understanding. All cultures and societies have their own culturally-informed framework for understanding health and illness. Psychology is based more on a western understanding or philosophical orientation and has emanated from a Eurocentric perspective or understanding. There are other orientations to the world that have more of cultural understanding instead of imperial or rational foundation might have more of a spiritual or holistic approach to understanding intellectual disability, challenging behaviours, health, wellness, illness and treatment.

This model is a representation of notions of challenging behaviour of persons with intellectual disability by the participants in the study. The challenging behaviour experience is the centre of persons with intellectual disability's being. It consists of various dimensions that may visible both internally and externally. The participants in the study had common general experiences and understanding of challenging behaviour concerning medical, psychological, spiritual/religious/traditional, and social issues.

6.5.1. Understanding of challenging behaviour

Participants understanding of challenging behaviour rise to the expected pattern of their beliefs. Lessons they learned from their family or ancestors are cultural patterns of beliefs, which are culturally based belief system. The importance of this model is considering the cultural component in understanding challenging behaviour and

intellectual disability. This study understood participants' narratives to understand or explain challenging behaviour. This study co-constructed an understanding of challenging behaviour into something that coincides with the participants viewpoint. They provided culturally sensitive interpretations on their children/learners symptoms and treatment for challenging behaviour.

The twenty-three participants in the study mentioned challenging behaviour based on their belief background. Participants understood challenging behaviours as culturally constructed behaviours that include possession of evil spirits, having ancestral callings, demonic attack, involuntary movements or spirits moving in the body, mental illness, hallucinations, and unusual behaviours. They also described challenging behaviours as socially constructed in that for a behaviour to be considered challenging, teachers and parents interpreted it as being, dangerous, frightening and stressful for example aggressiveness, self-injurious behaviours, stereotypical behaviours, inappropriate sexual behaviours, confusions and inability to care for oneself, etc. It is therefore vital that we should include the cultural aspect in explaining challenging behaviour.

6.5.2. The causal explanations of challenging behaviour

Among the participants in the study, beliefs about the causes of challenging behaviour often included a mix of culturally specific beliefs, myths, religious explanations, and biological, psychological, environmental and social factors. Most of the participants in the study mentioned cultural explanations as a cause of challenging behaviour. Some of the participants mentioned that challenging behaviour is God's will; others mentioned that it was because of a curse, witchcraft, bad luck, punishment.

Participants indicated that they will always consult with the sangoma. They mentioned that sometimes people can do things on you and the traditional doctor will be able to easily manage with that. Participants mentioned that they still rely much on the traditional doctors for many things in their life. They believe that the causes of challenging behaviour are some form of high power.

6.5.3. Approach to treatment

Most participants in the study believed in the approach to treatment that included integration of Eurocentric, traditional medicine and spiritual/religious practices. The strategies mentioned by the participants to treat the disease included a combination of the following; western medicine, use of religious waters, salts, other religious prayer practices, traditional herbs and worship of ancestors. They mentioned spirituality as a protective factor. They believe that spirituality is a foundation that shapes our personal beliefs by awakening awareness of ourselves and personal strengths within ourselves and others. In this case the strength of a priest or religious leader would include creativity of healing challenging behaviour by the powers he received from God to cleans demonic attacks. They have strong knowledge, practice or religion that they are subscribed to Christianity or religious healers.

Participants with a strong belief of traditional remedies had believed that they would only go to a traditional healer when they think that their child/learner has been exposed or invaded by an evil spell, possessed of evil spirits, has been unprotected and they have an evil spell on them, they would have a traditional healer to do the ritual of cleansing on them, especially when they show signs of challenging behaviours. They have the belief that "*badimo*" the ancestors have integral parts to play, they believe that if you do them proud they will always shield you. Participants believe that ancestors have a strong hand in restoring physical wellness and mental wellbeing. Rituals are believed to be series of actions performed in a prescribed order. Participants find support, hope and healing through ritual cleansing. Sangomas performs rituals using body or rhythms to witchcraft/evil spirits. The participants who only believe in Christian doctrines do not believe in ancestors or ancestral calling. They believe that only Christian healing and prayers cast black magic and also people who were infected with witchcraft.

Culturally informed approach to mental illness give the accurate care for participants depending on their beliefs. It is important to study cultural issues, when there is disparities in cultural attitudes and how others feel seeking or accepting treatment to get the care they are comfortable with. Western/Eurocentric methods of healing combined with cultural or religious healing will integrate social connections, beliefs and practices as

multi-faceted methods of healing. Recognising cultures' connection to healing can employ traditions as tools to help people recover spiritual and emotional balance. Modern medicine, healing and culture can partner to support our human potential for powerful responses to disease and illness. Healing traditions play an important role in the process for those people who keep close ties to their cultural identities.

6.6. Conclusion

Characteristics of the Biopsychosocial, as well as the African traditional worldview, are combined by this advanced model. The study shows that it is ok to accept multiple explanatory models. The study clarifies the cultural meaning of challenging behaviour and connects participants' cultural explanations with Eurocentric diagnosis. The biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery. This study explains that challenging behaviour of persons with intellectual disabilities must be conceptualized with the participants concerns or their cultural beliefs.

The African viewpoint gives the adapted BPS its distinctive quality by adding an element of culture into it. This model would be assumed relevant and applicable within the African context because it suggests a holistic approach to treatment in suggesting collaborative health care between mental healthcare providers, families, traditional healers and religious healers for challenging behaviour of persons with intellectual disabilities. The next chapter discusses the findings in relation to the literature.

CHAPTER 7

DISCUSSION

This chapter is aimed in reflecting the research findings in relation to the previous literature in this area. The chapter is structured into two parts, Part A and Part B. Part A discusses the shared experiences in relation to existing literature presented. The results contained three superordinate themes that emerged from the thematic content analysis which helped in directing the discussion pertaining to the research objectives. Part B will include the discussion of the psychological interpretations emanating from the study in relation to the literature.

PART A: DISCUSSION OF THE SHARED EXPERINECES IN RELATION TO LITERATURE

The participants in this study have shown an understanding of the concept of challenging behaviour, not from any definition provided by someone, but from their own interpretation of the behaviours from their children and/or learners with intellectual disability over a considerable period. Even though they had some common understanding, their unique experiences and causal explanations to characteristics that relates to challenging behaviour, were different according to their distinctive individual circumstances, and their attitude and coping skills.

7.1. Understanding the meaning of challenging behaviour

The twenty-three participants in the study mentioned challenging behaviour based on their belief background. Most of the participant mentioned challenging behaviour from a spiritual perspective. The participants in the study demonstrated varied beliefs about causal explanations of the challenging behaviour. The beliefs about the causes of challenging behaviour included a mix of both Western (biopsychosocial) and culturally specific beliefs and religious explanations. Some of the participants in the study associated challenging behaviour with bad luck, witchcraft and ancestral calling. This may reflect the participants' cultural health attributions, beliefs, and practices. Studies have shown that there is a relationship between attitudes (beliefs), particularly in relation to

intellectual disability and coping strategies (Lazarus & Folkman, 1984; Vaughn et al., 2009). Participants whose beliefs were that the challenging behaviour of persons with intellectual disabilities is God's will tend to use religious coping strategies and those whose beliefs were that it was a curse or bad tended to rely on traditional methods to cope.

Participants understood challenging behaviours as spiritually constructed behaviours that includes possession of evil spirits, having ancestral callings, demonic attack, involuntary movements or spirits moving in the body, mental illness, hallucinations, and unusual behaviours. They also described challenging behaviours as socially constructed in that for a behaviour to be considered challenging, teachers and parents interpreted it as being, dangerous, frightening and stressful for example aggressiveness, self-injurious behaviours, stereotypical behaviours, inappropriate sexual behaviours, confusions and inability to care for oneself, etc.

Many of the participants in the study were devoted to traditional/cultural understanding of the causes of challenging behaviour. Some of the participants in the study mentioned that they believe the disease is caused ancestral calling inherited from the history of the family, others believe it is caused by witchcraft, bad luck, misfortunes or fate. However, it is to be noted that for several uniquely personal reasons participants perceive psychotic symptoms, such as delusions usually associated with severe mental illness, as signs of a divine calling for persons with intellectual disabilities to become healers.

The finding that participants believe challenging behaviours signify a divine call to become healers and is thus regarded as a positive life experience has been similarly reported by researchers in the past. For example, Swartz (1998) reports that some care providers, such as families and religious healers, often conceptualise severe mental disorders, such as challenging behaviour, as spiritual illnesses and that *ukthwasa* (a divine call to be a traditional healer) in South Africa is believed to run in some families. Similarly, Sorsdhal et al. (2010), in a study involving traditional healers in South Africa, report that participants were seen to believe that *ukuthwasa* (a divine call to be a traditional healer) is not a mental illness but a positive state of health. They are also were seen to believe that it is necessary for the families of individuals called to serve as divine healers to organise initiation ceremonies, such ceremonies being characterised by performing rituals, offering

sacrifices, administering traditional medicines and communicating with family ancestors (Sorsdhal et al., 2010). Orley (1970) similarly reports that among members of the Baganda community in Central Uganda, being called to be a traditional healer necessitates the *initiate* constructing a shrine on his or her own homestead, collecting various small articles to be placed in the shrine and wearing small ornaments on his or her body. Subsequently, the initiate is required to organise a ceremony during which traditional doctors are invited to offer various articles and animals to the *balubaale* (spirits). According to Swartz (1998), failure to accept a divine call to be a healer is believed to lead to negative consequences, including *ukuphambana* (insanity).

Many of the parents also revealed that they find it difficult to raise their children at times because these challenging behaviours are not easy to manage. In some cases, the family had different views challenging behaviours. A mother would for instance accept the news, but the father or the child's siblings would not. In most cases the denial ended in time and most parents seem to have accepted the situation eventually. Most of the parents mentioned that their traditional healers, religion or church was the main force that helped them towards acceptance and gave them strength and peace. The current study concurs with Pilusa's (2006) findings regarding parents and teachers' understanding regarding intellectual disability. Respondents in this study understood the concept of intellectual disability from the interpretation of the behaviour of their own children over time. This was different to what Mbwilo, Smide and Aarts (2010) found in Tanzania, where the parents they interviewed did not have a good understanding of intellectual disability.

7.2. Perceived causal factors of challenging behaviour

The twenty-three participants in the study mentioned challenging behaviour based on their belief background. Most of the participant mentioned challenging behaviour from a spiritual perspective. Participants understood challenging behaviours as spiritually constructed behaviours that includes possession of evil spirits, having ancestral callings, demonic attack, involuntary movements or spirits moving in the body, mental illness, hallucinations, and unusual behaviours. The latter also believe mental illness to be caused by substance abuse from the mothers, head injuries and other biomedical causes, such as genes, neurological disorders, immature brain development and classifications of

intellectual disability. Participants also attribute mental illness to psychosocial causes, such as stress, abuse, bereavement and relationship problems and to socioeconomic factors, such as poverty and unemployment. They also described challenging behaviours as socially constructed in that for a behaviour to be considered challenging, teachers and parents interpreted it as being, dangerous, frightening and stressful for example aggressiveness, self-injurious behaviours, stereotypical behaviours, inappropriate sexual behaviours, confusions and inability to care for oneself, etc.

Few subthemes regarding the perceived causes of challenging behaviours among participants emerged from the data. These are: (a) perceived supernatural causes, (b) perceived biomedical causes, (c) perceived psychosocial causes and (d) perceived socioeconomic causes. The finding that participants believe challenging behaviours are due to multiple factors including supernatural causes, biomedical causes, psychoeconomic and psychosocial causes has similarly been found by researchers in the past (Helman, 2007; Kleinman, 1980; Patel, 1998). For example, Helman (2007) reports that multi-causal attributions of illness usually fall within the supernatural, social, natural and individual domains. Within the supernatural domain for instance, illnesses are caused by supernatural agents such as gods and spirits while in the natural domain illnesses are caused by natural conditions such as weather changes (e.g. excessive heat and coldness (Helman, 2007)). Because of the dynamic nature of explanatory models, it is common for patients and their families to hold varying and at times contradictory attributed causes of illnesses

7.2.1. Perceived supernatural causes of challenging behaviours

Most participants reported that they believe supernatural forces, such as demonic attacks and witchcraft cause challenging behaviours. The findings indicate that participants believe that, ancestral callings, witchcraft, black magic or generational curses cause challenging behaviour among persons with intellectual disabilities. Some participants indicated that they are terrified because of the uncertainty over witchcraft, which they believe possess them. According to participants, demonic attacks alter the biological constitutions of persons with intellectual disabilities, thereby enabling the latter to acquire the capacity to host the demons seen as challenging behaviours.

Some participants stated that family members deliberately sent demonic forces to cause challenging behaviour on their children due to family disputes. The other participant reported that ancestral calling is the cause of her mental illness because her late grandmother was also a traditional healer. Yet, the person with intellectual disability could possibly be suffering considerable challenging behaviours as a result of unmet attachment needs to that of his/her late grandmother. Participants are also seen to believe that unusual behavioural patterns associated with challenging behaviours manifest demonic attacks or ancestral calling among persons with ID as signs of a divine calling for persons with ID to become healers. Participants reported that some persons with ID develop challenging behaviours because they are cursed by their significant others because of jealousy among friends, family member and neighbours due to their foreseen success.

Some participants defined challenging behaviours as an act of God. Some participants believe that some disabilities are the result of lack of adherence to social morality and religious proclamations that warn against engaging in certain behaviour. To further explain this, some beliefs are based upon the assumption that some disabilities are the result of punishment from an all-powerful entity. Furthermore, the belief is that the punishment is for an act or acts of transgression against prevailing moral and/or religious edicts. The moral/religious model of disability is the oldest model of disability and is found in several religious traditions, including the Judeo-Christian tradition (Pardeck & Murphy 2012). According to one of the primary forms of moral and/or religious models of disability, disability should be regarded as a punishment from God for a sin or sins that may have been committed by the person with disability. Henderson and Bryan (2011) offer a thorough explanation of the moral and/or religious model of disability.

Religious causal attributions have been linked to the use of religious coping activities (Pargament, Koenig & Perez 2000). Gall et al., (2005) argue that attributions to God may help individuals preserve their belief in a just world. Some of the participants in the study were devoted Christians and tended to ascribe the cause of the challenging behaviours to God's will. For these participants, health and disease, life and death were seen to be in God's hands. These participants seem to have made an active decision to release

personal control to God over those aspects of their experience that fall outside their control. Pargament et al., (2000) argue that the act of surrendering control provides an emotionally overwhelmed individual some relief, comfort, and sense of security in that God is now in charge of the situation. Rather than entail a sense of fear over a perceived “loss of control”, a surrendering religious coping style paradoxically enhances spiritual well-being as well as the process of cognitive appraisal (Pargament et al., 2004). Several studies have found that religion play an important role in finding meaning in a stressful situation (Balboni & Peetel, 2017; balboni et al., 2007; Pargament, 1997).

The finding that participants believe supernatural factors cause challenging behaviour is consistent with findings by researchers in the past, who report supernatural forces as the perceived leading attributed cause of mental illness (Jacobosson, 2002; Patel, 1995). For example, in a review of research on explanatory models of mental illness in 11 sub-Saharan African countries, Patel (1995) reports that mental illness is frequently attributed to supernatural causes such as spirit possession and witchcraft. Patel (1995) argues that the view that *external* causes such as spirits and witchcraft cause both mental and physical illness is common in many African cultures. According to Patel (1995), spirits associated with mental illness include family spirits, community ancestors and evil and alien spirits. Family spirits and community ancestors are believed to be benevolent, although they can also cause illness and misfortune. Benevolent spirits can be upset in various ways, for example, when people break social taboos; evil and alien spirits, on the other hand, are basically malevolent and can cause illness in and other misfortunes to people randomly (Patel, 1995).

Similarly, Okello and Musisi (2006) report that members of the Baganda community in Central Uganda regard supernatural forces as the *ultimate* cause of challenging behaviour, the latter which is locally identified as *eByekika* (clan illness). The ultimate cause, in the context of Okello and Musisi’s (2006) study, accounts for *why* an illness is contracted. According to these authors, members of the Baganda community believe that behaviour, such as neglect of traditional rituals, lost kin, breaking of taboos and mixing of indigenous religious beliefs with foreign ones, comprise the ultimate causes of psychotic depression. For example, neglect of traditional rituals includes neglect and intermittent

performance of worship rituals for ancestral spirits and failure to attend to the family ancestral shrine.

Misfortunes such as mental illness are therefore perceived as reminders to family members of their unfulfilled duties regarding ancestral worship. Okello and Musisi (2006) also report that members of the Baganda community believe that lost kin can cause mental illness in two ways. The first instance involves erroneously giving a clan name to a child conceived by a woman outside clan circles. Angry family demons can cause the child to be affected by a mental illness as a means of expressing their displeasure for the lost kin. The second instance involves burial of a clan member in a foreign land. The spirit of a deceased member of the family is thought to possess a living relative as a means of compelling the affected family to search for the corpse in order to give it a decent burial in the family's ancestral burial grounds (Okello & Musisi, 2006).

In summary, participants reported that they believe supernatural forces cause challenging behaviour among persons with ID. Such perceived supernatural causes are thought to include demonic possession, witchcraft, curses and a divine call to be healers, which is ancestral calling.

7.2.2. Perceived biomedical causes of challenging behaviours

Most participants reported that biomedical factors cause challenging behaviours among participants. These causes include genetic predisposition and other health conditions, such as genetic conditions. These include things like Down syndrome and fragile X syndrome. Many participants reported that they believe intellectual disability to be hereditary. According to Donald et al. (2010), the chances for children who are born into a family where the parents themselves are intellectually handicapped to also inherit ID (particularly genetic deviations) is very high. Problems during pregnancy. Things that can interfere with fetal brain development include alcohol or drug use, malnutrition, certain infections, or preeclampsia. Problems during childbirth. Intellectual disability may result if a baby is deprived of oxygen during childbirth or born extremely premature. Illness or injury. Infections like meningitis, whooping cough, or the measles can lead to intellectual disability. Severe head injury, near-drowning, extreme malnutrition, infections in the brain, exposure to toxic substances such as lead, and severe neglect or abuse can also cause

it. Adnams (2010) furthermore explains that traumatic brain injury (TBI) plays a big role in the occurrence of ID in the South African context. She explains that although this (TBI) is one of the more easily preventable causes of ID, it is a problem in South Africa as a result of the high rate of road accidents and violence (physical assaults on children), of which TBI is often the after-effect.

7.2.3. Perceived environmental/psychosocial factors causing challenging behaviours

Some participants reported that psychosocial factors, namely, family conflicts, stress, abuse and trauma from loved ones can cause challenging behaviour among persons with ID. Researchers have in the past similarly found that life events involving significant loss, for instance, of loved ones, to be associated with mental illnesses (Brown & Harris, 1978; Smith, 2011). For example, Brown and Harris (1978) report that any significant loss involving, for example, children, relationships with partners and family members and valued assets, causes mental stress which leads to a mental illness.

7.2.4. Perceived socioeconomic factors causing challenging behaviours

Participants in this study reported socioeconomic factors such as poverty, malnutrition, lack of education and unemployment to cause intellectual disability. There is consensus among researchers that mental illness and socioeconomic status are inversely related. According to Yu and Williams (1999), social selection theory postulates that low socioeconomic status among people with mental illnesses occurs because of health-related downward mobility. Social selection theory assumes that mental illness prevents individuals from obtaining and/or keeping employment necessary to sustain or improve their socioeconomic status. People with mental illnesses may thus drift into lower socioeconomic groups or fail to climb out of low socioeconomic positions due to the incapacitating effects of their illnesses. Social selection theory also emphasises genetic explanations for variations in the risk of mental illness. In addition, it regards mental illness as a cause of considerable social and occupational impairment, for example, loss of employment, increased care-seeking costs and loss of income that, in turn, account for

the low socioeconomic status among people with mental illnesses (Lund et al., 2010; Titov, 2007).

In contrast, social causation theory postulates that mental illness is caused by socioeconomic adversities that people with a low socioeconomic status unduly experience (Yu & Williams (1999). A low socioeconomic status is associated with high levels of pathogenic conditions and few resources for coping with problems of living (Adler & Snibbe, 2003). Psychological distress, characterised by feelings of loss and disappointment, is common among poor people because of undue social adversity associated with severe life events that are also known as long-term threats (Brown & Harris, 1978). Such severe life events include diagnosis of a life-threatening illness in a family member, marital separation or threat, including death, and a major negative revelation about a significant other.

Moreover, unrelated life events may produce additive effects among poor people; apart from life events, low socioeconomic status is associated with provoking agents such as social exclusion, malnutrition and increased vulnerability to violence and trauma that cause and perpetuate mental illnesses (Lund et al., 2010). Diverse dimensions of low socioeconomic status in different social and cultural contexts that manifest social disadvantage and are risks for mental illness include gender, age, low levels of income and low levels of formal education (Patel et al., 1999). For example, Patel et al. (1999) report gender to be a risk factor for mental illness because of the multiple roles for women, violence against women and women's lower gender status. Lund et al. (2010) similarly report a low level of formal education to be positively associated with common mental disorders. Additionally, income inequality in liberalised market economies is associated with increased risk for mental illness, such as disparity in access to basic needs, for example, food, education and medical care as well as susceptibility to debt, the latter which causes considerable psychological stress among poor people (Lund et al., 2010; Patel et al., 1998; Saxena et al., 2007).

7.3. Coping strategies

This study assumed that when applied to illness beliefs, the beliefs and attitudes from a particular cultural group's worldview or cultural model of disease influence perceptions about the meaning an illness, the types of treatment or remedies that are useful, and the likely outcome of health behaviour related to the prevention and control of illness (Halbert et al., 2007). There are mainly few strategies that the parents and teachers indicated to be using to deal with challenges behaviour of persons with intellectual disabilities. These strategies are religious coping, traditional/cultural methods of copying, family and social support, and mental healthcare.

7.3.1. Religious coping

Most parents revealed that they are religious people and they believe in God. This helps them cope with the situation of having a child with ID. They accept their children bearing in mind that God comes in their lives in many ways. They also believed that it is just a faith test from God. The church community also helps them to deal with challenging behaviours much better; they have learned to accept things and complain less. Religious causal attributions have been linked to the use of religious coping activities (Shortz & Worthington, 1994). Gall et al., (2005) argue that attributions to God may help individuals preserve their belief in a just world. Some of the participants in the study were devoted Christians and tended to ascribe the cause of the challenging behaviour to God's will. For these participants, health and disease, life and death were seen to be in God's hands.

These participants seem to have made an active decision to release personal control to God over those aspects of their experience that fall outside their control. Pargament et al., (2000) argue that the act of surrendering control provides an emotionally overwhelmed individual some relief, comfort, and sense of security in that God is now in charge of the situation. Rather than entail a sense of fear over a perceived "loss of control", a surrendering religious coping style paradoxically enhances spiritual well-being as well as the process of cognitive appraisal (Pargament et al., 2004). Several studies have found that religion play and important role in finding meaning in a stressful situation (Peetet & Balboni, 2013; balboni et al., 2007; Pargamnent, 1997). Religion can help locate an event within the context of a "bigger picture" or purpose (Pargament, 1998).

Pentecostal churches is usually conducted in the form of group rituals, with “laying of hands” on patients and prayer performed for them. Okello and Neema (2007) similarly report the concept of being “born again” to be central to sacred healing. Similarly, rituals, including divination using tools, such as cards, bones, straws, shells and special stones, may also be used to diagnose and treat clients’ problems (Helman, 2007). Folk healers also often employ diagnostic techniques such as interpretation of dreams and visions and direct consultation with supernatural beings via trance (Helman, 2007). For example, patients and relatives, at times, disagree on the source of care despite holding seemingly similar beliefs about causes (for example, witchcraft) of mental illnesses (Okello & Neema, 2007). Such disagreement is often due to divergent religious beliefs among patients and their families; consequently, Christians do not seek care from traditional healers even if they believe witchcraft to be the cause of mental illnesses (Okello & Neema, 2007).

The use of religion as a coping mechanism appeared to be working for the participants in the study. Studies show that when people are confronted with illness, particularly mental illness, they may tend to engage in prayer and other religious practices more frequently (Peteet & Baloni, 2013). Most participants in the study were going to the Zion Christian Church (ZCC).

7.3.2. Traditional/Cultural methods of copying

Moreover, participants in their study indicated intellectual disability and challenging behaviour to be mainly caused by supernatural agents, such as witchcraft, and are thus to be treatable with traditional medicines. However, participants also informed challenging behaviour to be caused by both biomedical and supernatural agents and thus to be treatable by modern and traditional medicines. Participants informed that misconduct attracts punishment for the culprit, which includes spirit possession and subsequent mental illness (Okello & Musisi, 2006). Participants also informed that challenging behaviours can be effectively treated using traditional medicines. Secular healing, on the one hand, may include treatments by, for example, bonesetters, tooth extractors and herbalists. Sacred or ancestral healing, on the other, may include rituals performed by

spiritual healers especially to those who they believe have the powers to be traditional healers.

7.3.3. Family and Social support

While some participants explained that they did not receive any support from their family or anyone else because of being discriminated or for different reasons, many stated that their families and friends are there for them. As seen above, most of the parents available for the child are mothers. Fathers are often not available. Some single mothers explained the support they receive from their mothers and siblings because they accepted the condition and the child is comfortable around them. Since some parents were also affected by ID, some of them were assisted by their neighbours while most wished that the community could understand their children with intellectual disability and give them support.

Family support helped others to come to terms with the situation too. Many of the parents stated that they became more understanding of challenging behaviour after spiritual and ritual cleansing in their families. In many cases, however, the children are not accepting of the condition themselves due to the stigma attached to the disability. This causes a lot of pain for the parents and makes it almost impossible for them to accept the situation. It significantly delays the process of acceptance. Several studies have pointed out the necessity of examining adaptation to illness not only as an individual process but also as part of the family and the roles of the family members and partners (Lazarus & Folkman, 1984). The findings are in line with previous research (Tam, McKay, Sloan, & Ponsford, 2015) which also highlighted the importance of social relationship when family and community adapt to their illness to help cope with challenging behaviours.

7.3.4. Healthcare professionals

Some participants in this study rely on health care professionals to outline specific needs and services that will help persons with intellectual disabilities to thrive. Early intervention may include speech therapy, occupational therapy, physical therapy, family counseling, and training with special assistive devices, or nutrition services.

PART B: THE PSYCHOLOGICAL INTERPRETATION OF THE FINDINGS

The stories that the participants described in this study is consistent with the psychological explanations of how people perceive and experience challenging behaviour. To help make sense of this psychological journey, human development stages was used as a guide.

7.4.1. Human developmental stages

There are different stages of development that humans go through and this can be divided into prenatal, neonatal, infancy and childhood, adolescence, and adulthood development (Louw & Edwards, 2005). Louw and Edwards (2005) describe these stages: prenatal development begins when the woman's egg cell captures the sperm up until birth and there are stages of development that takes place until the woman is ready to give birth. Those stages are the germinal (from conception up to about one to two weeks), embryonic (from about two weeks until about eight weeks after conception), and the fetal (from the end of embryonic until birth) period. Whether the child develops well during all these stages, as seen in Adnams (2010), Donald et al., 2010 and Louw and Edwards' (2005) work, depends on a number of factors including the mother's diet, mother's health status, and level or types of drugs and medication taken by the mother. They (Adnams, 2010, Donald et al., 2010, Louw & Edwards, 2005) further explain that poor diet can result in certain abnormalities to the baby, including increasing chances of still born, low birth-weight, premature birth, deformities, retarded growth, poor intellectual development, and death during the first year of life. While maternal illness during pregnancy do not normally harm the unborn child, since most viruses and bacteria cannot permeate the placenta, some illness can unfortunately cross the placenta, including the HIV virus, if proper treatment is not taken (Adnams, 2010).

A wide variety of medication and drugs can also have a negative influence on the unborn child; these include alcohol, nicotine, and anti-depressants and they can result in problems such as mental retardation, low birth-weight and physical deformities, all of which may cause ID (Louw & Edwards, 2005). After the child is born a lot of factors determine the type of development he/she is going to have throughout his/her life; such factors include the environmental/contextual and socio-economic situations the child is

exposed to (Härkönen, 2007). These factors can have tremendous influence on the child's physical, cognitive/intellectual, social, emotional, and personality development (Adnams, 2010). The concerned special school accept learners/individual between 8 to 22 years of age, thereby dealing with learners in their middle childhood, adolescence and early adulthood stage.

7.4.2. Childhood

While early childhood spans from the age of 2 to 6 years, middle childhood is between the ages of 6 and 12 (Louw & Edwards, 2005). Louw and Edwards (2005) state that without proper nutrition, the physical development of a child in this stage is at risk of being stagnant because of problems like malnutrition and in such circumstances, the child's ability to be active/play/explore, develop proper motor skills, and in the process be able to socialise and thereby develop their social, emotional and personality skills may be jeopardised.

Ultimately, as Maulik, Mascarenhas, Mathers, Dua, & Saxena (2011) points out, such a child may have learning difficulties since their brain is likely to have been less stimulated. Piaget describes four stages of cognitive development in humans, and those are sensory-motor (birth - 2 years), pre-operational (2- 5 years), concrete operational (6 - 11 years), and formal operational (11 - adolescence) (Louw & Edwards, 2005).

Following Piaget's stages, the special school receives the children during their concrete development stage, and in this stage children are expected to have certain capabilities (as described by Piaget) including logical thinking about concrete objects, have a conversation, and be able to add and to subtract. They should have developed reversibility (can think in more than one direction) and decentration (can focus on more than one aspect of an object).

Piaget says the formal operational stage separate childhood from adolescence; at this stage abstract reasoning and hypothesising develops, and this stage should be the beginning of the ability to think like an adult; children should have developed selective attention skills, thereby advancing their information-processing skills here. Their memory-span should have improved as well by this stage (Berk, 2001). Certain factors also

determine how well or bad children go through these stages. These include availability of parents, activeness of parents to the child's development, the influence of the parents on the child, and the type of home environment that child grows under (Louw & Edwards, 2005).

7.4.3. Adolescence

A stage between childhood and adulthood is the adolescence stage, and it spans from about 12 years to 19 years of age (Pettersen & Albers 2001). Louw and Edwards (2005) describe that although human development occurs throughout the entire life span, it is during this stage that more physical changes occur, more cognitive skills improve, individual's social involvements become intense and their views about themselves become stronger. They, (Louw & Edwards, 2005) continue to state that there is also a lot of biological and emotional changes during this stage, and a lot of children recognize their personality, identity and world-view during this stage. Like all the developmental stages, as Vasliner and Connolly (2003) describes it, the success or failure of this stage depends on a lot of factors, including the parent-adolescence relationship, peer group influence, and the type of the overall environment at which the development take place.

7.4.4. Adulthood

The period between adolescence and old age is adulthood and it is divided into early (approximately 20 to 40 years), middle (40 to 65 years), and late adulthood (from 65 years of age) (Louw & Edwards, 2005). By the time individuals reach adulthood, it is expected that they should be able to take full responsibilities of their lives, be having full abilities to use their executive functioning skills (including planning, problem-solving skills, and proper decision-making skills), and be able to be independent. Erikson in his psychosocial stages (cited by Louw & Edwards, 2005) describes that failure to assume adulthood for individuals results in isolation/loneliness, stagnation and despair.

Because of the nature or the characteristics of the children/individuals affected by ID and of the type of the environment they live in (South African village with its characteristics) as described in this study, most of the children are unable to follow the development as described here; they are behind in many aspects including cognitively, socially and

emotionally. In fact, the type of the environment/social context they live in have played a huge role in causing their disability. There is poverty, therefore the village is characterised by a shortage of basic resources, including effective health services and education, which both lead to limited pre-natal tests and examinations, and ignorance regarding healthy lifestyle during pregnancy.

In this way, as described earlier, the possibility of birth-related infections, injuries, stillborn babies, and underweight new-born babies (resulting from nutritional deficiencies among other things) increases in this village. This is supported by Adnam's (2010) report that nutritional deficiencies lead to multiple biological and psychosocial risks, a reduction in motor skills, behaviour deficits and impairments in cognitive, physical, neurological and sensory skills/performances.

Children who come to the school in their middle childhood often do not have the skills their peers without ID have; they cannot properly add or subtract, often cannot recognize colours or objects and their language/communication skills are poor. Such children, even when they reach the adolescent stage, are often unable to present the cognitive/intellectual, social and emotional qualities children their age possess. They struggle to read, write, construct proper sentences, develop healthy intrapersonal and interpersonal relationships and they lack other important life skills including self-regulatory and emotional skills. They also still need assistance for hygiene skills and other practical skills that their counterpart teenagers already possess. The same is true with those entering early adulthood; they often cannot take full accountability of their lives because of the disability, and most still need pushing and constant assistance to go about their day-to-day lives and chores.

This reality of these children/individuals means that the parent-child dyad is often strained and dysfunctional and the developmental stages and Bronfenbrenner's social systems (as described earlier) are disrupted. One must bear in mind however that although all the children/individuals are affected by SID, the extent of the lack of their conceptual, social, emotional and practical skills differs and this is as a results of many other factors including the number of disabilities they have, the type of cognitive/developmental deficits they face, and the structure of family they come from.

The ecological model of human development proposes a set of ecological subsystems that envelop the child and influence him or her in a reciprocal manner (Bronfenbrenner, 1979). At the core of these subsystems is the family: home and family play a key role in children's development, learning and their overall wellbeing (Beveridge, 2005). However, according to the ecological model, as much as the family affects a child's development, the child also influences the life of his or her family (Swick & Williams, 2006). Thus, a child who has a disability has a special effect on his/her family (Seligman & Darling, 2007).

Bronfenbrenner summed up this interconnectedness between individuals and their environment by stating that the interaction between factors in the individual's maturing biology, their immediate family or community environment, and the societal landscape fuels and steers their development (Tudge, Mokrova, Hatfield, & Karnik, 2009). In the present study, the environment is not necessarily convenient for balanced, maximised development opportunities of its occupants because of the reasons described in the study (a South African village, lacking basic resources including proper housing, health-related services, employment and education opportunities and infrastructure). While this state of the environment generally affects all the people who live in the community depending on their own personal circumstances, the families affected by ID have further challenges that make the environment even more unfriendly and unpleasant. This is in terms of all the systems as described by Bronfenbrenner (microsystem, exosystem, mesosystem, macrosystem and chronosystem). The children's intellectual and adaptive functioning deficits make both their own lives and those of their parents/families difficult. They (children) often have problems communicating their feelings with people around them (at home, school, and the broader community), have challenges following social rules/norms, and often show behavioural problems including self-injuries, aggression, sibling conflicts, conduct disorders, and emotion-regulation difficulty.

As seen in the study, this whole situation impact on their teachers and parents. The parents have lots of behavioural, emotional/psychological, social, and financial/economic problems as a result. These include alcohol abuse, depression, burnout, dependence on the government social/disability grant, and constrained social lives. As seen in the study, such challenges lead to further problems for these parents and children, including causing

dysfunctional families and broken homes/mother-headed families. This means that these families' developmental processes are often stagnant, and their quality of life is poor, and eventually their lifespan is likely to be shortened as a result. The next chapter is comprised of summary, conclusions, and recommendations of the study.

CHAPTER 8

SUMMARY AND CONCLUSION

8.1. Introduction

This chapter starts with summary of the findings, encountered limitations, recommendations and the implications for future research are discussed at length. Lastly, the conclusion of the study is presented. The summary is divided into three themes which understand of challenging behaviour, causal explanations and beliefs about appropriate interventions to cope with challenging behaviour.

8.2. Summary of the results

A qualitative explorative approach was used to investigate the understanding and description of challenging behaviour. The aim of this study was to conceptualise and develop an explanatory model for challenging behaviour in persons with intellectual disability by parents and teachers. The explorative design helped the research to explore different understandings towards challenging behaviour. The study was conducted in Capricorn District, Limpopo Province. The two special schools namely *Bana ba Thari* and Benedict and Hope were selected. The researcher was also helped by the school principals to select the teachers and parents most suitable for the study. A semi-structured interview guide with open-ended questions was used to address the objectives of the study. The data was collected in the boardrooms of the two schools and at the participant homes, using the languages that the participants understood better. Data collected was later translated to English. Collected data was analysed by thematic content analysis. Themes and subthemes were used to explore and describe challenging behaviours of persons with intellectual disabilities. This study was approved by the Turfloop research ethics committee, and the following ethics were adhered to, informed consent, confidentiality, anonymity, privacy, respect, voluntary participation, no harm to participants.

The study was guided by the Afrocentric and the bio-psycho-social theories. This study was aimed at developing an explanatory model for challenging behaviours in persons with intellectual disabilities. The study was guided by the following objectives: to understand and describe the notions of challenging behaviours in persons with intellectual disabilities by parents and teachers; to determine causal explanations of challenging behaviours; to establish parents' and teachers' beliefs about appropriate interventions for challenging behaviours in persons with intellectual disabilities and based on the above, develop and articulate an explanatory model on challenging behaviour in persons with intellectual disabilities.

Twenty-three participants were sampled in the study. The sample comprised of eleven teachers and twelve parents. This study also constituted people with different educational levels, 20% of the participants had primary school education, 50% secondary school education and 30% having tertiary school education. The participants' ages ranged from 26 years to 59 years. Their mean age was 41 years.

The study concludes that the interpretations by parents and teachers of person with intellectual disabilities regarding the understanding, descriptions, beliefs and appropriate coping mechanisms for challenging behaviour are important.

8.2.1. The meaning of challenging behaviour

This theme addressed the importance of the notions of challenging behaviour from parents and teachers of persons with intellectual disabilities. The study was able to address this theme sufficiently. In summary, to establish the meaning of challenging behaviour, the study explored two important aspects that were crucial in determining meaning for an experience of a specific phenomenon. Firstly, the study explored challenging behaviour as related knowledge, most participants reported that they understand challenging behaviour mainly as mental illness, unusual behaviours such as self-injurious behaviour, aggression towards others, destruction of property, inappropriate social and sexual conduct, screaming, non-compliance, and eating inedible objects. Secondly, the study set out to explore uncommonly reported aspects of challenging behaviour as hallucinations (habitually in and out of touch with reality), ancestral calling,

demonic attacks, involuntary movements of spirits moving inside the body and possession of evil spirits. In general, this study has found complex concepts regarding challenging behaviour. Conceptualisation of challenging behaviour was based mainly on supernatural attributions, such as spirit possession, and behavioural symptoms often exemplifying mental illness.

8.2.2. The causes of challenging behaviour

The findings in this study reveal that beliefs about the causes of challenging behaviour frequently included cultural/religious/spiritual beliefs, myths and explanations. Fewer participants mentioned western (biomedical) explanation as the cause of the challenging behaviour. This, though, appears to have been in line with the already identified poor knowledge about the challenging behaviour in the African context. Fewer subthemes regarding the perceived causes of challenging behaviour in this study emerged from the data. These are perceived supernatural causes, perceived biomedical causes and perceived psychosocial/environmental causes. Within the supernatural domain for instance, illnesses are caused by supernatural agents such as gods and spirits which includes, witchcraft or bad luck, generational curses, bad luck. This theme also addressed religious causal explanations which revealed that some participants in the study ascribed the cause of challenging behaviour to the will of God as they were dedicated Christians. These participants believed that everything is controlled by God regardless of whether it is good or bad.

The biomedical explanations addressed in this study indicated that a mental illness to be possibly due to biological causes, for example, chemical imbalances in the brain. The challenging behaviour occurs during the psychiatric illness. It is present across a range of personal and social situations, although it may be more severe in certain settings. The findings in this study also revealed environmental factors such as poverty and stress as one of the causal explanations. The results indicated that psychological distress, characterised by feelings of loss and disappointment, is common among marital relationships where some women will be stressed, abused or perhaps loose a partner through death or separation while pregnant and that would result in the possibility of having a child with intellectual disability. The results also explained that poor people

because of undue social adversity associated with severe life events people with socioeconomic status unduly experience challenging behaviour because a low socioeconomic status is associated with high levels of mental problems which could also lead to intellectual disability.

In conclusion the findings that participants believe challenging behaviour in persons with intellectual disabilities are due to multiple factors including supernatural causes, biomedical causes, and psychosocial causes. Therefore, cultural beliefs are likely to significantly influence coping efforts following an intellectual disability diagnosis since they influence how individuals' manifest symptoms.

8.2.3. Appropriate interventions for the treatment of challenging behaviour

The findings in this study show that the approaches that the participants took to manage challenging behaviour were influenced by their knowledge, attitudes, and beliefs about the causes of challenging behaviour in persons with intellectual disability. Cultural, religious and specific health beliefs generated from these approaches to treatment were important determinants of the meaning that challenging behaviour is ascribed to intellectual disability.

Participants in this study indicated challenging behaviour to be mainly caused by supernatural agents, such as witchcraft, and are thus to be treatable with traditional medicines. However, participants also informed challenging behaviour to be caused by both biomedical and supernatural agents and thus to be treatable by modern and traditional medicines. The findings that participants believe religious and traditional healers provide health education to PWID is surprising in this study as researchers have in the past reported sacred and secular healers to be very secretive about their knowledge regarding care for clients. All participants reported the provision of treatment by the collaboration of mental health workers, families, religious healers and traditional healers to be another form of care for PWID.

Participants informed that misconduct attracts ancestral punishment for the culprit, which includes spirit possession and subsequent mental intellectual disability. Participants also informed that challenging behaviour can be effectively treated using traditional medicines.

They explained that secular healing may include treatments by, for example, bonesetters, tooth extractors and herbalists. Sacred healing, on the other, may include rituals performed by spiritual healers. Sacred healing, especially in the ZCC and Pentecostal churches, is usually conducted in the form of group rituals, with “laying of hands” on patients and prayer performed for them, the concept of being “born again” to be central to sacred healing. Religious values such as faith in God were found to be very important. Similarly, some participants also relied on ZCC to give them instructions regarding their specific treatment options or remedies in the context of their challenging behaviour. They particularly mentioned the teas, oils and salts that the Zion Christian Church (ZCC) priests prescribe for treatment after diagnosing their clients.

In this study some parents of the same child would dissent when it comes to the preferred type of treatment. For example, parents and relatives, at times, disagree on the source of care despite holding seemingly similar beliefs about causes for example, witchcraft as a cause of challenging behaviour. Such disagreement is often due to divergent religious or traditional beliefs among members of the families; consequently, Christians do not seek care from traditional healers even if they believe witchcraft to be the cause of intellectual disability and vice versa. Some Participants believed that support from their family members ease the stress of having a child with intellectual disability because they usually assist with taking care of the person with intellectual disability. Some participants in the study mentioned that they would consult with their traditional doctors, psychologists, family members and also religious leaders to try to find as many answers as possible for treatment of intellectual disability. This suggests a strong belief of a holistic approach and trusting approach to treatment for most participants in this study.

8.3. Towards the Bio-Psycho-Socio-Cultural Model to explain challenging behaviour

Based on the findings of the study, an explanatory model to explain challenging behaviour of persons with intellectual disabilities was developed. This model combines the components of both the BPS and the Afrocentric paradigm which considered the individuals bio-psychosocial and cultural experiences. The BPS emphasises the interplay of biological (genetic predisposition), psychological or behavioural (lifestyles, explanatory styles, health beliefs), and social factors (family relationships, socioeconomic status,

social support) in the explanation of pathogenesis and health aetiology (Bowling, 2014). This model will provide a blueprint for research, a framework for teaching, and a design for action in the real world of health care (Masters, 2013). This model further asserts that the determinants for, and the prognosis of, mental health difficulties are the result of an interaction between biological, psychological, and social factors—with no factor having a “monopoly” on the explanation and/or cure (Babalola, Noel & White, 2017).

The Afrocentric paradigm in this study brings aspects that lack in the BPS. It helped assembled the African cultural point of view from parents and teachers. This also assisted the researcher to wholly understand challenging behaviour in an African setting through parents and teachers’ views.

The findings show that culture in this study influences the labelling and expression of as well as the response to challenging behaviour. The findings also show that different social and cultural contexts, such as the schools, family and health care settings determine the understanding to explain experiences of challenging behaviour they are faced with. The model identified in this study figured the influence of culture when participants explained challenging behaviour, thus making it important to collaborate cultural contexts with the biological, psychological and social mental health care to understand challenging behaviour as well as to design and deliver appropriate mental health care interventions.

This model added the cultural formulation which will improve the diagnostic validity that will assist psychologists to align the treatment recommendations for persons with intellectual disabilities and their families with their preferred method of treatment. That would ultimately serve to prevent dissatisfaction, non-adherence and poor response to treatment on the part of patients. This model best suits cultural formulation which is consistent with cultural competence and is aimed at improving mental health care in contexts of cultural diversity.

Based on the above considerations of this model, appropriate mental health care requires the correct and appropriate contextualisation of challenging behaviour for persons with intellectual disabilities and care providers in social and cultural contexts. This model ensures that careful attention to culture may prevent stereotypical attitudes among

clinicians towards diverse patients. Using this model, clinicians may, for example, discover “what really matters” for persons with intellectual disabilities, their families and for themselves, which is normally a combination of cultural and their psychological understanding within specific local word.

This model will also help clinicians to reframe culture in this regard as “intellectual disability meaning” and to enhance effective communication with patients, they may also need to ask individualised questions, such as, “what do you call this problem?”

Generally, the concept of this model provides a useful framework for collaboration of clinicians, traditional healers and religious healers to make effective diagnoses of mental health conditions and to provide a culturally relevant care of challenging behaviour for persons with intellectual disabilities.

8.4. Implications of the study

Participants’ response to their understanding of challenging behaviour is mostly guided by their culture. It is, therefore, critical to recognise cultural factors that impact on intellectual disability. It is critical to recognise and appreciate the impact of knowledge, understanding, and beliefs about challenging behaviour among persons with intellectual disability that are informed by the cultural reality of the people affected. These cultural beliefs are likely to significantly influence coping efforts following an intellectual disability diagnosis since they influence how individuals’ manifest challenging behaviours.

Based on the findings of this study, the following implementations for future studies are made:

8.4.1. Implications for theory

The model unites the elements of the BPS and the Afrocentric viewpoint. The BPS provides a useful framework for understanding people’s behaviours in relation to an illness, but its major criticism was that it does not account for cultural or normative factors (Rosenstock, 1974). The Afrocentric viewpoint allows for a culturally based relevance and dimension that is lacking in the BPS. The importance of this model is considering the cultural component in understanding challenging behaviour and ID. This model

conceptualises intellectual disability with parents and teachers concerns or their cultural beliefs. It is vital to know and understand cultural factors that impact on challenging behaviour of persons with intellectual disabilities. Traditional/spiritual beliefs are perceived as important factors to cultural backgrounds of persons with intellectual disabilities.

This model believes that culture connects to healing and recovery therefore; mental health services to intellectual disability of Africans should also incorporate the appreciation of their worldview and cultural way of life. This model construct healing as a blend of mental health practice (blend of BPS and culture) we should also appreciate the role that traditions and religion play as a belief for treatment. The model can be applied as part of the intervention strategies in the broad mental health field to help people with intellectual disabilities.

8.4.2. Implications for policy

The findings show that persons with intellectual disability (PWID) have significant and lifelong needs across the health, social care and education spectrum and there is no single sector that can fully meet the needs of individuals and their families across their lifespan. A traditional/cultured approach for PWID and their families it is required and it is essential that a policy framework exists to: 1) Determine and define the support-needs of the PWID in terms of service delivery and then, 2) Determine the appropriate government departmental roles and responsibilities in such a cultural-needs model.

A fundamental shift in the policy direction should be proposed where departments should re-align their services to placing emphasis on cultural dimensions and how PWID and their families can be supported through traditional/cultural service delivery level instead of families trying to fit governmental approach. This requires high-intensity support across all life environments because this will potentially assist to better manage ID and challenging behaviour. This support should involve more staff because cultural and other specific health beliefs generated from these approaches to treatment will be important determinants of the meaning that challenging behaviour is ascribed to intellectual disability.

Formulating a transversal policy framework that includes cultural practices will promote effective and efficient service delivery and should provide clear guidelines to services providers and departments. Care that is provided outside of institutional and hospital setting near as places where people live and study should be implemented in the National Mental Health Policy framework and strategic Plan 2020-2030.

8.4.3. Implications for practice

The proposed culturally sensitive model offers fresh insight into the appreciation of the importance of cultural issues in the management and care for challenging behaviours of persons with intellectual disabilities. The study has demonstrated the importance of people's cultural background, including beliefs how they experience illness. Clinical psychology, as a profession, should embrace this if it were to be relevant to the majority of South Africans. Cultural competence is essential to all five elements of patient/client management, namely, evaluation, diagnosis, treatment, and rehabilitation. Developing rapport, collecting and synthesizing patient data, recognizing personal concerns about function, and developing the plan of care for a person with intellectual disability requires cultural competence. Psychological interventions geared toward the people identified as Africans should include culturally tailored services. By providing culturally appropriate services to people with diverse belief systems, the possibility of their achieving a better QOL and more positive health outcomes will be enhanced.

8.4.4. Implications for future research

The aim of the study was to conceptualise and develop an explanatory model for challenging behaviour in persons with intellectual disabilities. The researcher recommends that another study should be done to evaluate the developed model.

The researcher recommends that a quantitative study should be done to get the overall notions of parents and teachers to have a broader understanding of challenging behaviour, in which more participants should be used.

The hope is that the results of this study will inspire interventions from concerned parties guided by the nature of the results to initiate measures to help manage the challenges that parents, and teachers face while raising (and living with) these children.

Also, the researcher hopes that other researchers would want to continue the research, particularly in rural and township areas, on this topic after this study. This will hopefully mean more help and support in general for people with ID and their families as the disability receives more attention.

8.5. Limitations of the study

The limitations of the study include the following:

- Only Sepedi speaking teachers and parents were used and this limits the knowledge and activities used by parents and teachers of other ethnic groups. The study, therefore, cannot generalise the results beyond this population group.
- The study sample comprised of twenty-three participants. The size of the sample is not large enough to allow generalisation of the results.

Furthermore, another limitation was that respondents were recruited in the special school setting, as opposed to the clinical or community setting. This means that the experiences of parents of children with intellectual disability who are not enrolled in special schools have not been tapped.

8.6. Recommendations

- The study also revealed that holistic management approaches for challenging behaviour of persons with intellectual disabilities needs to be implemented. The holistic management which should involve healthcare professionals, psychology professionals, traditional healers, religious healers, families, and support from non-governmental organisations.
- There is a need for health professionals to consider disclosing and communicating the mental disability of the child with the parents immediately after birth – to ask parents their preferred copying mechanism.
- The Department of Social Development should communicate more effectively the financial assistance available for parents and children with intellectual disabilities. Relevant health professionals (for example, psychologists and social workers)

together with spiritual healers (traditional healers and religious leaders) need to collaborate to educate and train parents and teachers of children with intellectual disabilities on the technical aspects of caring for children with the condition.

8.7. Conclusion

This chapter summarised the methodology and findings that were used in the study. It also covers the limitations of the study, and recommendations were made based on the finding of the study. The recommendations were addressed to policy makers and different government departments. This study has identified various interpretations of challenging behaviour. The meaning of challenging behaviour that the participants recognised and described to this journey was influenced by several variables such as their religious and cultural belief system, health care, and available support from family members and friends. The study has revealed limitations in existing models of challenging behaviour, which explains that they may not necessarily be applicable in every setting as they have lacked socio-cultural factors. This model suggests collaborative health care between mental healthcare providers, families, traditional healers and religious healers for challenging behaviour of persons with intellectual disabilities.

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APPENDICES

Appendix 1(a): Interview guide

Objective	Interview questions
<p>1. To understand and describe the notions of challenging behaviours in persons with intellectual disabilities by parents and teachers</p>	<p>a). I would like you to share with me your perception of challenging behaviour?</p>
	<p>b) As a person who is taking care of an individual diagnosed with intellectual disability, I would like you to share with me your understanding of events and factors that could have led to your family member's challenging behaviour?</p>
	<p>c) I also would like you to explain, according to your understanding and experiences, what challenging behaviour is?</p>
<p>2. To determine causal explanations of challenging behaviours in persons with intellectual disabilities by parents and teachers</p>	<p>d) After realizing that the child/learner has intellectual disability, what did you think was the cause behind this condition?</p>
	<p>e). May you explain to me what would cause challenging behaviour in the child/learner?</p>

<p>3. To establish parents' and teachers' beliefs about appropriate interventions for challenging behaviours in persons with intellectual disability</p>	<p>f) Please share with me your beliefs about challenging behaviour of the child/learner with intellectual disability?</p> <p>g) Kindly share with me what you consider appropriate interventions for challenging behaviour for the child/learner with intellectual disability?</p>

Appendix 1 (b) Tsela ya go sepetsa dipotsiso tja dipoledisano

Maikemisetso	Dipositso tja dipoledishano
<p>1. Bjalo ka bahlokomedi (batswadi goba barutisi) ba bana bao ba se baitekenalego monaganong, ke kgopela go bolela le lena mabapi le tšeo le bonago ele thlohlo tša maitshwaro a banaba.</p>	<p>a). Ke rata ge le ka abelana lenna ka ponelo pele ya dithlotlo tša maitshwaro a?</p> <p>b). Jwalo ka mohlokomedi wa bana bao ba sa itekanelego monaganong, ke rata ge o ka abelana lenna kwišišo ya tseo di kabago di hlotse dithlotlo tše?</p> <p>c). Ke rata gape gore o hlalose go ya ka kwišišo ya gago le boitemogelo bya gago gore naa dithlotlo tše ke eng?</p>
<p>2. Ka ge le phetše kudu le bana bao ba se baitekanelego monaganong mosekolong sa lena, ke eng seo le bonago se hlola maitshwaro a bona a go se amogelege.</p>	<p>d). Morago gago lemoga gore ngwana goba morutwana wa gago o na le go se itekanele monaganong, o ile wa gopola gore boemo byo bo hlotšwe ke eng?</p> <p>e). O ka nhlalose tša gore ke eng seo se ka hlalago dithlotlo tše mo ngwaneng goba morutwana wa gago?</p>

<p>3. Ke magato afe a makaone a go laola maitshwaro a go tshwenya a bao basa itekanelago kgopolong.</p>	<p>f). Ka kgopelo, abelana lenna seo o se dumelago mabapi le dithlotlo tša maitshwaro a bana goba barutwana ba gago ba go se itekanelego menaganong?</p>
	<p>g). Ka kgopelo, abelana lenna mokgwa wa maleba wo o ka o šomisago go thuša bana goba barutwana ba go se itekanele monaganong?</p>

Appendix 2: Participant consent letter

Department of Psychology

University of Limpopo

Private Bag X1106

0727

Date:

You are sincerely appreciated for demonstrating concern in this study that focuses on the experiences and notions of parents and teachers of persons with intellectual disabilities in Capricorn District. The purpose of this study is mainly to develop a culturally informed explanatory model for challenging behaviours in persons with intellectual disabilities.

Your responses will remain strictly private. The researcher will surely not try to identify you with your responses to the interview questions or to disclose your name as a participant in the study. May you please be advised that participating in this study is voluntary and that you certainly have the right to terminate your participation at any time.

Please answer all the questions and reflect your true notions. Your participation and support in this study is very crucial and appreciated. Thank you.

Sincerely

Tebogo Lekota

Date

Prof T Sodi Date
Supervisor

Appendix 3: Consent form to be signed by participant

CONSENT FORM

I ----- hereby agree to participate in a Doctorate Research project that focuses on the experiences and notions of parents and teachers of persons with intellectual disabilities in Capricorn District.

The purpose of the study has been fully clarified to me. I acknowledge and understand that I am contributing generously and freely without being forced in whatsoever way to do so. I truly understand that I can dismiss my participation in this study at any point should I wish not to continue and that my decision will not in any way affect me negatively.

I understand that this is a research project, whose purpose is not necessarily to benefit me personally. I understand that my details as they appear in this consent form will not be linked to the interview schedule, and that my responses will remain confidential.

Signature:

Date: _____

Appendix 4: Permission letter to the Department of Education

Department of Psychology
University of Limpopo
Private Bag X1106
Sovenga
0727

Date:

The Circuit Manager
Department of Education
Capricorn District
Private Bag X Polokwane
0700

RE: PERMISSION TO CONDUCT RESEARCH IN TWO SPECIAL SCHOOLS FOR PERSONS WITH INTELLECTUAL DISABILITIES IN CAPRICORN DISTRICT

My name is Tebogo Lekota, a Doctorate candidate in the Department of Psychology at the University of Limpopo. I am leading a study on: "Towards an explanatory model for challenging behaviour in persons with intellectual disabilities in the Capricorn District, Limpopo Province". The purpose of my study is specifically aimed at understanding and describing parents and teachers' views regarding challenging behaviours in persons with intellectual disabilities.

I hereby apply to be allowed permission to conduct this research in the following two schools in your circuit, namely: *Bana ba Thari* and *Ga-Molepo* Special Schools for Persons with Intellectual Disabilities. The researcher will ensure confidentiality regarding the identity of the participants in this research project. The participants will definitely by

explained well by assuring them about the voluntary nature of this study and will be freed at any time should they wish to withdraw from the study.

The methods of data collection will be unstructured individual interviews with the parents and teachers.

Sincerely,

Tebogo Lekota
Doctorate Student

Date

Appendix 5: Letter of Ethical Clearance (University Of Limpopo Ethics Committee)



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

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING: 09 October 2018

PROJECT NUMBER: TREC/183/2018: PG

PROJECT:

Title: Towards an explanatory model for challenging behaviour in persons with intellectual disabilities in the Capricorn District, Limpopo Province
Researcher: PTN Lekota
Supervisor: Prof Tholene Sodi
Co-Supervisor/s: Prof S Govender
School: Social Sciences
Degree: PhD Psychology


PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

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

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Finding solutions for Africa