

**THE CHALLENGES OF INDIAN PARENTS CARING FOR ADULT CHILDREN  
WITH INTELLECTUAL DISABILITIES**

**By**

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**A mini-dissertation submitted in partial fulfilment of the requirements for the  
degree**

**MASTER OF SOCIAL WORK**

**IN HEALTH CARE**

**MSW**

**(HEALTHCARE)**

**in the**

**FACULTY OF HUMANITIES**

**DEPARTMENT OF SOCIAL WORK AND CRIMINOLOGY**

**UNIVERSITY OF PRETORIA**

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**AUGUST 2017**

## **DECLARATION**

I hereby declare that: “The challenges of Indian parents caring for adult children with intellectual disabilities” is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, and that this dissertation was not previously submitted by me for a degree at another University.

Sharita Fiona Singh

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## **ACKNOWLEDGEMENTS**

I would like to express my gratitude and thanks first and foremost to God the Almighty, without whom none of this would have been possible. Secondly, I would like to thank my family for their unwavering support and belief in me.

I am indebted to a great number of people who have contributed to this research project. I wish to express my thanks to the following people and institutions for making this research project possible:

- The parents who participated in my research study, I am extremely grateful to each and every participant for their willingness, kindness, patience and support to share their life stories with me.
- Mrs N.J. Bila, my supervisor, for her assistance, continuous guidance and support throughout the whole process.
- The Department of Social Work and Criminology at the University of Pretoria.
- My colleagues and management at Weskoppies Hospital – Social Work Department, for their ongoing love, support and guidance.
- The staff and management at the Laudium Mental Health Society for their support in this research study.

**TITLE: Challenges of Indian parents caring for adult children with intellectual disabilities**

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**DEPARTMENT: Social Work and Criminology**

## **ABSTRACT**

Intellectual disability is a lifelong condition that brings with it many medical, psychological, social and cultural challenges that affect parents caring for their adult children in their family home. Therefore, the present study is aimed at identifying these challenges so that services and programmes can be developed and implemented. This, as a result, will enhance service delivery to ensure a better quality of life for both parents and their children.

The goal of the study was to explore and describe the challenges of parents caring for adult children with intellectual disabilities within the Indian community in Laudium. The researcher conducted the study using a qualitative research approach. This type of research was applied in nature and a collective case study design was utilised.

The sampling technique chosen was purposive and included snowballing as a secondary technique. The 12 participants that were selected met the following criteria of the present study: a South African citizen, an Indian from any religion, a father or mother of an adult child or children (20 years and older) with an intellectual disability, an adult child who attends the day care centre at the Laudium Mental Health Society and/or a parent who accessed services such as counselling/support at the Laudium Mental Health Society or whose child accessed these services. The researcher conducted semi-structured one-to-one interviews because this type of data-collection method provides more flexibility for both the researcher and the participants regarding the interview schedule.

The present study found that parents displayed a fair insight into and understanding of their children's intellectual disabilities despite not receiving a formal diagnosis. There are many medical challenges for parents when living with adult children with intellectual disabilities such as associated health conditions, co-morbidities and psychiatric disorders.

The present study further found that the emotional experiences encountered by parents caring for adult children with intellectual disabilities ranges from positive emotions (hope and acceptance) to negative emotions (despair and hurt).

Many parents chose to be self-employed because it offered flexible working hours in order to take care of their children with intellectual disabilities. The parents and adult children with intellectual disabilities experienced a lack of a social and community life because of behavioural problems, lack of facilities available for children with physical disabilities as well as stigma within the community. The most supportive system parents experienced when caring for adult children with intellectual disabilities is the immediate family members such as spouses and other children.

Furthermore, the parents require assistance with regards to physical care when caring for their adult children with intellectual disabilities because they are getting older. Despite receiving a disability grant, parents required an additional source of income to pay for special equipment, medical expenses, therapies, clothing, food and toiletries for their adult children with intellectual disabilities.

Due to racial segregation, parents could not access special schools in the community for their children with intellectual disabilities. The parents hoped that their adult children with intellectual disabilities would die before them. The families of adult children with intellectual disabilities believed that cultural influences were the cause of the intellectual disability.

In conclusion, there are many biopsychosocial challenges that parents faced when caring for adult children with intellectual disabilities. Parents who are middle aged or elderly are in need of care and support themselves but they find themselves still providing care and support to their children and therefore various interventions within the community are needed to support and promote the well-being of the parents and their children.

The present study highlights the need for an inter-disciplinary team approach that should be available to the parents and their children throughout their lifecycle to assist with the various biopsychosocial challenges they experience. Parents and families of children with intellectual disabilities should receive information sessions/workshops regarding the intellectual disability and how to overcome the challenges they experience.

It is further recommended that an Indian residential facility within the community that caters for all the religious and cultural requirements/needs is established and the community should be educated about mental illness and specifically intellectual disability to prevent stigma and discrimination.

**Key words:**

- Intellectual disability,
- Biopsychosocial,
- Challenges,
- Adult children,
- Indian community

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# CHAPTER ONE

## GENERAL OVERVIEW TO THE RESEARCH METHODOLOGY

### 1.1 INTRODUCTION

Intellectual disability is a lifelong condition (Molteno, 2007:524) and it is more common than most people realise (SA Federation..., 2015). The South African Federation for Mental Health asserts that 4 out of 100 South Africans are affected by some level of intellectual impairment (SA Federation..., 2015). The importance of caring for people with intellectual disability within the community has increased with the move towards de-institutionalisation of care (Molteno, 2007:524). Therefore, there is an increase in the number of adult children with intellectual disabilities who are being cared for by their parents in their family home (Cuskelly, 2006:20).

As a result, parents of adult children with intellectual disabilities experience demands and strains that affect their capacity to cope (Cuskelly, 2006:20). Cuskelly (2006:21) indicates that many parents need to provide assistance with activities of daily living, advocate for their children to obtain appropriate services and are constantly concerned about their future. Molteno (2007:526) further adds that parents experience loss of earnings from having to give up work or face additional costs from medical bills, special equipment, bedding and clothing and, in addition, experience social isolation and relationship strain.

The present study focuses on the challenges faced by parents caring for adult children with intellectual disabilities within the Indian community in Laudium. Laudium is a suburb that is located southwest of central Pretoria, where the majority of the residents are of the Indian race group. The Laudium Mental Health Society was selected for the purpose of the study because it renders services to adults with intellectual disabilities.

### 1.1.1 DEFINITION OF KEY CONCEPTS

- **Intellectual Disability**

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM 5), (APA, 2013:31) defines intellectual disability as

deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience. The deficits result in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings.

The terms such as mental handicapped and mental retardation were used in the past to refer to intellectual disability (Kaneshiro, 2013; Molteno, 2007:524). The terms developmental disability and learning disability are also used interchangeably for intellectual disability (Kaneshiro, 2013; Molteno, 2007:524). In the present study, the term intellectual disability will be used.

- **Parent**

Hornby (2010:1066) defines a parent as "a person's father or mother". In the context of the present study, a parent is defined as either a biological father or a mother of an adult child who has an intellectual disability.

- **Caring**

Caring refers to the "act or process of looking after people by undertaking tasks that they are unable to do for themselves" (Harris & White, 2013:52). For the purpose of the present study, caring characterises the relationship between parents and their children where the parents have frequent contact with their children and provide emotional, physical, psychological and financial support to them.

- **Adult children**

*Segen's Medical Dictionary* (2012) defines an adult as a "...person which has attained full growth or maturity." A child is defined as "a son or daughter of any age"

(Hornby, 2010:243). For the purpose of the present study, adult children are defined as the biological sons or daughters who are 20 years and older and who are cared for by their parents due to their intellectual disability.

## **1.2 THEORETICAL FRAMEWORK**

The biopsychosocial model proposed by George Engel in 1977 was used in the present study (Browne, 2012:21). This model is based on the general systems theory developed by Ludwig von Bertalanffy. One of the basic assumptions of this theory is that “systems exist within systems and therefore nothing exists in isolation.” This assumption forces professionals to develop a holistic view of the patient, rather than to focus on parts of their problem (Gould, 2010: 16; Ross & Deverell, 2010:5).

Visser (2012:25) mentions that “a system consists of various parts or subsystems that are related and interact with one another” and the interactions “between these parts and changes in them affect the system as a whole. The system itself is a unit or a whole that is more than the sum of its parts.” This theory links to the biopsychosocial model because it helps to understand family boundaries, family communications, family roles and family problem solving can all have a substantial impact on issues seemingly unrelated to the patient’s home life (Kaplan & Coogan, [sa]:20).

The biopsychosocial model offers a holistic alternative to the prevailing biomedical model because one must attend simultaneously to the biological, psychological and social dimensions of the illness in order to understand and respond adequately to patients’ suffering (Borrell-Carrió, Suchman & Epstein, 2004:576). Hatala (2012:52) further adds that the biopsychosocial model is “an important attempt to incorporate the patient’s psychological experiences and the social or cultural context into a more comprehensive framework for understanding disease, illness and health.”

The prefix bio refers to the biological aspects represented by, amongst others; the genetic, biochemical and physical factors that influence a patient’s problem and may lead to helpful medical interventions (Kaplan & Coogan, [sa]:19). In the present study, the biological factors that were investigated included the parent’s insight into

their child's intellectual disability, cause of intellectual disability, associated health conditions, co-morbidities and psychiatric conditions, medication and therapy.

The term psycho alludes to the psychological factors which allow the professional to assess and select interventions for developmental and psychological issues that have altered the normal development of both self-efficacy and self-esteem (Kaplan & Coogan, [sa]:19). Browne (2012:21) mentions that emotional problems can be caused by and result from health problems. In the present study, the psychological factors that were investigated included the emotional reactions of parents caring for an adult child with an intellectual disability; namely despair, hope, hurt and acceptance.

Social refers to family relationships, socio-economic status and social support (Hatala, 2012:51). Browne (2012:21) mentions that an individual's social functioning and health status are directly impacted by environmental factors. The social support systems of patients can influence their health status significantly and families can provide important support and assistance during times of health crisis or they can represent barriers to optimal care (Browne, 2012:21). In the present study, the social factors that were investigated included employment, the impact of social and community life on the family and the child, support systems (immediate family, extended family, domestic workers, neighbours and friends), influences on marital and sibling relationships, finances, types of resources parents require when caring for adult children in the community, community reactions, future planning and the role of culture.

Parents face many challenges in coping with their adult child with an intellectual disability. These challenges take a progressive toll on their health and psychological well-being (Song, Mailick & Greenberg, 2014:122). The biopsychosocial model was therefore used in the present study because it addressed an array of issues including parental inadequacies, loss of employment, educational opportunities, stigma of mental illness, rejection by family, burden of care, broken and destructive relationships and various forms of exploitation and abuse. These are all challenges that parents caring for an adult child with an intellectual disability may face (Smith, 2007:639).

People interact with many different systems such as family systems, educational systems, social service systems, employment systems and religious systems (Zastrow, 2012:45). Social work is a discipline based upon a strengths-based model of assessment and intervention which is based on the premise that all individuals have the capacity for growth and change (Robinson, Dauenhauer, Bishop & Baxter, 2012:179). By using this model in the present study, the researcher can devise strategies for social work interventions that will promote the well-being of parents caring for adult children with intellectual disabilities. Strategies include helping the parent and adult child to seek and develop problem-solving skills, strengthening, coping and developmental capacities, addressing the relationship between the parent/adult child and the systems they interact with and link them with needed resources, providing services and opportunities and investigating the systems seeking to reform them to meet the needs of the parent/adult child more effectively (Zastrow, 2012:45).

### **1.3 RATIONALE AND PROBLEM FORMULATION**

The first and most important step of the research process is formulating a research problem (Kumar, 2014:64). Fouché and Delpont (2011a:108) assert that problem formulation serves as an effective point of departure that broadens the focus of the study and articulates the specific problem that will be investigated by the researcher.

Parents provide a lot of support to their adult children with an intellectual disability, but they also require support themselves (Unwin & Deb, 2011:189). It is important to understand the challenges of these parents in order to “identify potential risk factors and provide appropriate and effective services” to them (Unwin & Deb, 2011:189). In South Africa, due to the lack of agreement on definitions and terminologies as well as a wide variation in understanding of these, has contributed to problems in accurate collection and interpretation of epidemiological data (Adnams, 2010:436). A search for academic journals on Ebsco Discovery Service with the keywords “*Challenges of Indian parents caring for adult children with intellectual disabilities*” between 2006 and 2016 revealed 1460 journal articles. However, none of the studies in the articles focused specifically on Indian parents caring for an adult child with an intellectual disability within the South African context (i.e South African Indian

parents caring for adult children with intellectual disabilities). The only studies which were conducted in the South African context was a study by Pulusa (2006) which explored the impact of intellectual disability on family functioning in the Waterberg district in the Limpopo province and a study by Trollope (2014) which explored the impact of socio-economic factors in raising a child with a mental disability in the North-West of Pretoria.

Social Workers who work with people with intellectual disabilities and their families are presented with challenges due to increased longevity (i.e. when the life of a person with an intellectual disability is not prolonged, they would not pose a challenge). The Social Workers often lack sufficient skills and knowledge to provide appropriate interventions due to lack of awareness, research and formal education (Robinson et al., 2012:176). The present study could therefore make a valuable contribution to the field of social work. Identification of the challenges that parents face when caring for adult children allows for the development of appropriate interventions. These may include creating awareness of intellectual disability thus helping to eradicate stigma and discrimination amongst this vulnerable group, providing psycho-education: on the disability, associated health conditions, medication and resources available in the community as well as providing support to the family system to allow it to cope with the challenges more effectively.

The research question for the present study is:

**“What are the challenges of Indian parents caring for adult children with intellectual disabilities?”**

## **1.4 GOAL AND OBJECTIVES OF THE STUDY**

### **1.4.1 Goal of the study**

The goal of the present study was to explore and describe the challenges of Indian parents caring for adult children with intellectual disabilities.

### **1.4.2 Objectives of the study**

The objectives of the present study include:

- To conceptualise and describe intellectual disabilities in adult children.
- To explore and describe the care required for adult children with intellectual disabilities.
- To explore and describe the biopsychosocial challenges of parents caring for adult children with intellectual disabilities.
- To explore the role of culture in caring for adult children with intellectual disabilities.
- To devise strategies for social work interventions that can broadly promote the well-being of parents of adult children with intellectual disabilities.

### **1.5 RESEARCH QUESTION OF THE STUDY**

Knowledge about families caring for people with intellectual disabilities comes mainly from an organized body of literature from the United States (US) and United Kingdom (UK) (Ghosh & Magana, 2009:180). Therefore, the present study is relevant because it addresses the problems faced by parents caring for adult children with an intellectual disability within the South African Indian context. The present study may therefore not only benefit the parents but also the adult children with an intellectual disability because the identification of the challenges allows for appropriate services and programmes to be developed and implemented that will enhance service delivery and ensure a better quality of life.

### **1.6 RESEARCH DESIGN AND METHODOLOGY**

A qualitative approach was employed in the present study. The research type used was applied research. The research design was a collective case study. The population of the present study was Indian parents who have adult children with intellectual disabilities and are accessing services at the Laudium Mental Health Society. Semi-structured one-to-one interviews were conducted. In Chapter 3, a

more detailed description of the research methodology as well as ethical aspects applicable to the present study are discussed.

## **1.7 LIMITATIONS OF THE STUDY**

The following were unavoidable limitations that were encountered during the present study:

1. The researcher recruited 12 participants during the data gathering process but some participants withdrew their consent to participate and therefore the researcher had to ask the active participants to refer other potential participants for the present study.
2. The researcher initially intended to focus on the mild to moderate level of severity of the intellectual disability but had to increase the range to include severe intellectual disabilities because of the newer participants. It is, however, important to note that the level of severity was not a criterion for selection of the participants.

## **1.8 OUTLINE OF THE RESEARCH REPORT**

The final product of this research is a mini-dissertation which is structured as follows:

- In Chapter 1, an overview to the research methodology is discussed with regards to: the definition of key concepts in terms of Indian parents caring for adult children with intellectual disabilities, the biopsychosocial theoretical framework, rationale and problem formulation, goal and objectives of the present study, research question of the present study, research design and methodology and limitations of the present study.
- In Chapter 2, a literature review is presented on the challenges of parents caring for adult children with intellectual disabilities. The literature review explores and describes the challenges of parents caring for adult children with intellectual disabilities giving an overview of intellectual disability and discussing the psychosocial implications for parents with adult children with intellectual disabilities in the family, the implications of an adult child with an

intellectual disability in the care of parents as well as the effects on sibling relationships with adult children with intellectual disabilities. The researcher refers to relevant policies and legislation, the role of culture in caring for adult children with intellectual disability in the Indian community and the role of the Social Worker in assisting parents caring for adult children with intellectual disability.

- In Chapter 3, the research methodology is discussed and themes and sub-themes are identified using transcripts from interviews conducted the participants, which acknowledged and represented the challenges and experiences of the participants in the present study.
- In Chapter 4, the goal and objectives of the present study are explained by highlighting the main findings of the study. Conclusions are drawn from the present study and recommendations are also made on the key findings of the present study.

In the next chapter, Chapter 2, a literature review is presented on the challenges of parents caring for adult children with intellectual disabilities.

## **CHAPTER TWO**

### **LITERATURE REVIEW ON THE CHALLENGES OF PARENTS CARING FOR ADULT CHILDREN WITH INTELLECTUAL DISABILITIES**

“There is no greater disability in society, than the inability to see a person as more.” – Robert M. Hensel

#### **2.1 INTRODUCTION**

Intellectual disability, or the currently favoured term ‘intellectual developmental disorder’, is not a mental illness but a lifelong condition that brings with it many potential mental health, medical and social challenges that vary as the individual and family move through different life stages (Bentley & Molteno, 2015:599).

Prior to de-institutionalisation, people with intellectual disabilities were housed in large institutions and generally excluded from community life but now more and more people with intellectual disabilities are living in the community and therefore require care within community health facilities (Bentley & Molteno, 2015:599). In the researcher’s opinion, within the Indian community, parents tend to not send their children to residential care/frail care facilities out of fear of them being judged as bad parents by the community and also the widespread conviction that family members should be taken care of within the family home. Therefore, parents will only consider residential care/frail care facilities as their last resort or option.

Primary health care workers such as Social Workers must therefore develop the necessary skills and learn management principles to ensure that the mental health and medical needs of people with intellectual disabilities are met through their entire lifespan (Bentley & Molteno, 2015:599). Therefore, it is important that social work intervention strategies are implemented as soon as the diagnosis has been made and to educate and support families as they move through the different stages of their life cycle.

People with intellectual disabilities have been severely marginalised and stigmatised on a worldwide scale historically; societally but also through discriminatory policies,

laws, actions and inactions enforced by decision makers in all community spheres (Nichol & Adnams, 2016:530). Therefore, caring for people with intellectual disabilities brings distinct challenges to management and care (Nichol & Adnams, 2016:530). It is the researcher's belief that, because of South Africa's history of apartheid, people with intellectual disabilities and their families within the Indian community have experienced further marginalisation and stigmatization due to being in the double (race and disability) minority groups.

Parents caring for adult children with intellectual disabilities suffer greater levels of psychological stress, may experience loss of earnings from having to leave their employment or face additional expenses due to needed clothing, bedding, special equipment and medical bills (Molteno, 2007:526). Molteno (2007:526) further states that exhaustion from caring for the adult child may interfere with relationships. The adult child's difficult behaviour may also limit the parents' social life. Siblings also experience problems such as embarrassment. Friends and relatives may worsen feelings of isolation by being unsure how to help. Single parents are often socially isolated. It is evident that parents caring for adult children with intellectual disabilities experience various biopsychosocial challenges.

In this literature review section, an overview on intellectual disability will be provided and the psychosocial implications for parents with adult children with intellectual disabilities in the family will be discussed. Additionally, the implications of an adult child with intellectual disabilities in the care of parents and the effects on sibling relationships will also be discussed. This section will further include an overview of policies and legislation that are relevant to intellectual disability, the role of culture in caring for adult children with intellectual disabilities in the Indian community and the role of the Social Worker in assisting parents caring for adult children with intellectual disabilities.

## **2.2 CONCEPTUALISATION OF INTELLECTUAL DISABILITY**

In this section, the conceptualisation of intellectual disability will be discussed in terms of the definition of intellectual disability, diagnostic criteria, epidemiology, levels of severity of intellectual disability, assessment of intellectual disability,

associated health conditions, co-morbidities, behavioural problems, psychiatric symptoms and psychiatric disorders as well as management of intellectual disability.

### **2.2.1 Definition of intellectual disability**

An intellectual disability is usually present at birth or originates in the early years of childhood and may result in individuals having difficulty understanding abstract concepts, adapting to some of the demands of daily life and the ability to learn (Community Living Ontario, 2015). When the brain is damaged and not able to function properly as a result of a car or other accident or through disease such as meningitis or stroke, it is said that the person has an intellectual disability (SA Federation..., 2015). These two definitions show that an intellectual disability can occur at any stage of a person's life.

In the past, terms such as 'mental handicap' or 'mental retardation' were used to describe this condition. These terms are, however, no longer used due to stigmatising (Kaneshiro, 2013; Molteno, 2007:524). The South African Federation for Mental Health proposes to rather "refer to a person with an Intellectual Disability, with the accent on the person rather than the disability" (SA Federation..., 2015).

### **2.2.2 Diagnostic criteria**

According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, certain criteria need to be met in order to be diagnosed with an intellectual disability. These are discussed in the next section.

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM 5) (APA, 2013:33) defines intellectual disability/intellectual developmental disorder as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains." The following three criteria must be met (APA, 2013:33):

- Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.

- Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation and independent living, across multiple environments, such as home, school, work and community.
- Onset of intellectual and adaptive deficits during the developmental period.

This diagnostic criterion appears to be holistic because it looks at all aspects of a person's life and it also takes into account cultural factors of a person.

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders assists professionals in diagnosing intellectual disabilities but it is also important to be aware of the prevalence of intellectual disability in South Africa.

### **2.2.3 Epidemiology**

Intellectual disability is the most common developmental disorder that affects a large number of individuals and is part of a broad group of heterogeneous conditions (Nichol & Adnams, 2016:531). Intellectual disability has an impact on families, communities and societies because of the complex nature of the condition and the fact that it is usually life-long. This as a result, constitutes a major public-health problem (Nichol & Adnams, 2016:531).

#### **2.2.3.1 Prevalence**

Kaneshiro (2013) indicates that intellectual disability affects about 1 to 3% of the world's population. In South Africa, accurate collection and interpretation of epidemiological data has been hampered by a lack of agreement on definitions and terminologies as well as a wide variation in understanding of these (Adnams, 2010:436). Adnams (2010:437) mentions that 3 nationwide studies in South Africa have attempted to describe the epidemiology of intellectual disability. The National Disability Survey of 1999 estimated the prevalence of intellectual disability at 1.1%. The National Census Survey in 2001 estimated the prevalence of intellectual disability at 0.5%. A further national survey in 2007, which examined severe intellectual or learning disability, yielded a prevalence of 0.27%.

The relative occurrence of mild, moderate, severe and profound severity is about 85%, 10%, 4% and 2%, respectively (Nichol & Adnams, 2016:532). In the present study, the challenges of parents caring for adult children with mild, moderate and severe intellectual disability are explored. Nichol and Adnams (2016:532,533) report that in a meta-analysis of 52 worldwide studies, the global prevalence of intellectual disability was estimated to be 10.37 per 1000 (1.0%) people, while in South Africa the prevalence rates of between 1 and 2% for all intellectual disability to 17% for mild intellectual disability were reported. Nichol and Adnams (2016:533) further report that male predominance of all intellectual disabilities is at a 3:2 ratio.

In the UK, about 60% of the adults with intellectual disabilities live at home with their families (Unwin & Deb, 2011:187). In Taiwan, 93% of adults with intellectual disabilities live with their families who take care of them (Chou, Fu & Chang, 2012:133). In the US, 75% of adults with intellectual disabilities live at home with family caregivers (Hasman & Zafron, 2010:34).

Cuskelly (2006:20) mentions that in Australia, “there are 38100 parents aged over 45 years whose son/daughter with an intellectual disability lives with them, with 4100 parents carers who are over 65.” In the US, one quarter (25%) of the parents who take care of their adult children with intellectual disabilities are over 60 years old (Hasman & Zafron, 2010:34). Chou, Fu and Chang (2012:133) and Cuskelly (2006:20) mention that the majority of primary caregivers of adults with intellectual disability are mothers.

Based upon the above statistics, it is revealed that the majority of adult children with an intellectual disability are cared for by their parents. These parents experience challenges in providing care and therefore one of the objectives of the present study is to make recommendations for social work interventions that can broadly promote the well-being of parents of adult children with intellectual disabilities.

#### **2.2.3.2 Aetiology**

Nichol and Adnams (2016:534) state that no reliable data is available on the aetiology of intellectual disability in South Africa. However, clinic-derived reports suggest that a number of causes of intellectual disability in South Africa have a similar prevalence to those of developed countries. Nichol and Adnams (2016:534)

further states that studies conducted by Kromberg et al. (2008) reported in the rural population congenital aetiology in 20.6% of affected children, an acquired aetiology in 6.3% and an undetermined aetiology in 73.1%, while Klientjes et al. (2006) reported that in the Western Cape Province the prevalence of intellectual disability was estimated at 3%.

There are four categories of risk factors (biomedical, social, behavioural and educational) that interact across time, including the lifespan of the individual and across generations from parent to child as described by the American Association on Intellectual and Developmental Disabilities (Nichol & Adnams, 2016:533).

- **Biomedical risk factors**

Biomedical risk factors are usually related to genetic conditions or acquired conditions such as pre-natal factors, peri-natal factors and post-natal factors (Nichol & Adnams, 2016:533). Pre-natal causes include various dysmorphic syndrome disorders, chromosome disorders, inborn errors of metabolism and developmental disorders of brain formation, such as hydrocephalus or spina bifida, toxic and teratogenic influences such as malnutrition and fetal alcohol exposure (Einfeld & Emerson, 2008:824). The peri-natal causes include prematurity, birth injuries, birth asphyxia and neonatal disorders such as septicaemia and placental insufficiency (Einfeld & Emerson, 2008:824; Nichol & Adnams, 2016:533). The postnatal causes include intellectual disability associated with seizures, toxic disorders such as lead poisoning, head injuries, infections such as meningitis and degenerative disorders such as the leukodystrophies, malnutrition and chronic social and sensory deprivation (Einfeld & Emerson, 2008:824).

- **Social, behavioural and educational factors**

Biomedical factors are influenced by environmental factors, including psychosocial influences such as a lack of environmental stimulation, poverty, social deprivation and lack of opportunity to learn or practice skills (Nichol & Adnams, 2016:533).

### **2.2.3.3 Prevention**

Molteno (2007:526) states that prevention of intellectual disability is closely related to aetiology. However, establishing a cause does not necessarily imply that there is

opportunity for prevention but it is the first step. Prevention strategies include comprehensive and efficient paediatric services, good perinatal care and genetic counselling (Molteno, 2007:526).

In South Africa, the most common preventable cause of intellectual disability is foetal alcohol syndrome and prevention is based on a three-tiered approach of universal strategies “aimed at providing information to the whole community; targeted strategies geared towards intervention in high-risk groups, and clinically indicated strategies involving case management of pregnant women who are known to be drinking” (Molteno, 2007:526).

In the researcher’s opinion, foetal alcohol syndrome seems to be an unlikely cause of intellectual disability in the Indian community as Indian women were prohibited from consuming alcohol especially amongst the older generation (since it was considered taboo or is frowned upon).

#### **2.2.4. Levels of severity of intellectual disability**

The American Psychiatric Association (DSM 5) (APA, 2013:33) suggest that there are four levels of severity of intellectual disability, which are defined on the basis of adaptive functioning and not intelligence quotient (IQ) scores.

Table 1 shows the levels of severity of intellectual disability, as determined by assessing function in three different domains:

- the conceptual domain,
- the social domain, and
- the practical domain (APA, 2013:34, 35, 36).

The American Psychiatric Association has published older versions of the DSM and it is likely that some of the adults have been formally diagnosed based on DSM III or DSM IV. Prior to the DSM 5, the degree of severity of the intellectual disability was based primarily on IQ levels and not on assessing their functioning in the three domains as shown in Table 1.

It was, therefore, proposed that the adult children in the present study should be reassessed according to the DSM 5 criteria to allow for more appropriate

interventions, to ensure a better quality of life, in terms of accessing appropriate services. Identifying the correct levels of severity will allow for enhancement services provided at day care centres. In the researcher's opinion, professionals such as Social Workers and Occupational Therapists can design activities and programmes that will provide improved stimulation in the weaker domains.

**Table 1: Levels of severity of intellectual disability**

<b>SEVERITY LEVEL</b>	<b>CONCEPTUAL DOMAIN</b>	<b>SOCIAL DOMAIN</b>	<b>PRACTICAL DOMAIN</b>
<b>MILD</b>	<p>For preschool children, there may be no obvious conceptual differences. For school-age children and adults, there are difficulties in learning academic skills involving reading, writing, arithmetic, time or money, with support needed in one or more areas to meet age-related expectations.</p> <p>In adults, abstract thinking, executive functioning (i.e., planning, strategizing, priority setting, and cognitive flexibility), and short-term memory, as well as functional use of academic skills (e.g., reading, money management), are impaired. There is a somewhat concrete approach to problems and solutions compared with age-mates.</p>	<p>Compared with typically developing age-mates, the individual is immature in social interactions. For example, there may be difficulty in accurately perceiving peers' social cues. Communication, conversation, and language are more concrete or immature than expected for age. There may be difficulties regulating emotion and behaviour in age-appropriate fashion; these difficulties are noticed by peers in social situations. There is limited understanding of risk in social situations; social judgment is immature for age, and the person is at risk of being manipulated by others (gullibility).</p>	<p>The individual may function age-appropriately in personal care. Individuals need some support with complex daily living tasks in comparison to peers.</p> <p>In adulthood, support typically involves grocery shopping, transportation, home and child-care organizing, nutritious food preparation, and baking and money management. Recreational skills resemble those of age-mates, although judgement related to well-being and organization around recreation requires support. In adulthood, competitive employment is often seen in jobs that do not emphasize conceptual skills. Individuals generally need support to make health care decisions and legal decisions, and to learn to perform a skilled vocation competently. Support is typically needed to raise a family.</p>

Source: Adopted from American Psychiatric Association (DSM 5) (APA, 2013:34)

**Table 1: Levels of severity of intellectual disability (continued)**

<b>SEVERITY LEVEL</b>	<b>CONCEPTUAL DOMAIN</b>	<b>SOCIAL DOMAIN</b>	<b>PRACTICAL DOMAIN</b>
<b>MODERATE</b>	<p>All through development, the individual's conceptual skills lag markedly behind those of peers. For preschoolers, language and pre-academic skills develop slowly. For school-age children, progress in reading, writing, mathematics, and understanding of time and money occurs slowly across the school years and is markedly limited compared with that of peers.</p> <p>For adults, academic skill development is typically at an elementary level, and support is required for all use of academic skills in work and personal life. Ongoing assistance on a daily basis is needed to complete conceptual tasks of day-to-day life, and others may take over these responsibilities fully for the individual.</p>	<p>The individual shows marked differences from peers in social and communicative behaviour across development. Spoken language is typically a primary tool for social communication but is much less complex than that of peers. Capacity for relationships is evident in ties to family and friends, and the individual may have successful friendships across life and sometimes romantic relations in adulthood. However, individuals may not perceive or interpret social cues accurately. Social judgement and decision-making abilities are limited, and caretakers must assist the person with life decisions. Friendships with typically developing peers are often affected by communication or social limitations. Significant social and communicative support is needed in work settings for success.</p>	<p>The individual can care for personal needs involving eating, dressing, elimination, and hygiene as an adult, although an extended period of teaching and time is needed for the individual to become independent in these areas, and reminders may be needed. Similarly, participation in all household tasks can be achieved by adulthood, although an extended period of teaching is needed, and ongoing supports will typically occur for adult-level performance. Independent employment in jobs that require limited conceptual and communication skills can be achieved, but considerable support from co-workers, supervisors, and others is needed to manage social expectations, job complexities, and ancillary responsibilities such as scheduling, transportation, health benefits, and money management. A variety of recreational skills can be developed. These typically require additional supports and learning opportunities over an extended period of time. Maladaptive behaviour is present in a significant minority and causes social problems.</p>

Source: Adopted from American Psychiatric Association (DSM 5) (APA, 2013:35)

**Table 1: Levels of severity of intellectual disability (continued)**

<b>SEVERITY LEVEL</b>	<b>CONCEPTUAL DOMAIN</b>	<b>SOCIAL DOMAIN</b>	<b>PRACTICAL DOMAIN</b>
<b>SEVERE</b>	Attainment of conceptual skills is limited. The individual generally has little understanding of written language or of concepts involving numbers, quantity, time, and money. Caretakers provide extensive supports for problem solving throughout life.	Spoken language is quite limited in terms of vocabulary and grammar. Speech may be single words or phrases and may be supplemented through augmentative means. Speech and communication are focused on the here and now within everyday events. Language is used for social communication more than for explication. Individuals understand simple speech and gestural communication. Relationships with family members and familiar others are a source of pleasure and help.	The individual requires support for all activities of daily living, including meals, dressing, bathing, and elimination. The individual requires supervision at all times. The individual cannot make responsible decisions regarding well-being of self or others.  In adulthood, participation in tasks at home, recreation, and work requires ongoing support and assistance. Skill acquisition in all domains involves long-term teaching and ongoing support. Maladaptive behaviour, including self-injury, is present in a significant minority.

Source: Adopted from American Psychiatric Association (DSM 5) (APA, 2013:36)

**Table 1: Levels of severity of intellectual disability (concluded)**

<b>SEVERITY LEVEL</b>	<b>CONCEPTUAL DOMAIN</b>	<b>SOCIAL DOMAIN</b>	<b>PRACTICAL DOMAIN</b>
<b>PROFOUND</b>	<p>Conceptual skills generally involve the physical world rather than symbolic processes. The individual may use objects in goal-directed fashion for self-care, work, and recreation. Certain visuospatial skills, such as matching and sorting based on physical characteristics, maybe acquired. However, co-occurring motor and sensory impairments may prevent functional use of objects.</p>	<p>The individual has very limited understanding of symbolic communication in speech or gesture. He or she may understand some simple instructions or gestures. The individual expresses his or her own desires and emotions largely through nonverbal, non-symbolic communication. The individual enjoys relationships with well-known family members, caretakers, and familiar others, and initiates and responds to social interactions through gestural and emotional cues. Co-occurring sensory and physical impairments may prevent many social activities.</p>	<p>The individual is dependent on others for all aspects of daily physical care, health, and safety, although he or she may be able to participate in some of these activities as well. Individuals without severe physical impairments may assist with some daily work tasks at home, like carrying dishes to the table. Simple actions with objects may be the basis of participation in some vocational activities with high levels of ongoing support. Recreational activities may involve, for example, enjoyment in listening to music, watching movies, going out for walks, or participation in water activities, all with the support of others. Co-occurring physical and sensory impairments are frequent barriers to participation (beyond watching) in home, recreational, and vocational activities. Maladaptive behaviour is present in a significant minority.</p>

Source: Adopted from American Psychiatric Association (DSM 5) (APA, 2013:36)

In order to determine the level of severity (mild, moderate, severe or profound) of intellectual disability, a child or adult will be assessed on difficulties they experience in the conceptual (development of language and academic skills), social (development in social and communicative behaviour) and practical domains (development of care for personal needs) as outlined in Table 1.

### **2.2.5 Assessment of intellectual disability**

The goal of the diagnostic assessment is to determine the nature of the problem, identify the aetiology and suggest potential interventions as well as address issues of the prognosis (Nichol & Adnams, 2016:535). The following should be considered when assessing a person for a possible intellectual disability (Nichol & Adnams, 2016:535,536):

- Medical and neurodevelopmental history
- Family and social history
- Clinical examination
- Psychometric and adaptive functioning

In the researcher's opinion, Social Workers that work in psychiatric hospitals, play a pivotal role in assisting the multi-disciplinary team (psychiatrists, psychologists, occupational therapists and nursing staff) in diagnosing mental health care users by providing a comprehensive report regarding the medical, neurodevelopmental, family and social history. Therefore, it is crucial that Social Workers working in a psychiatric setting understand the conceptualisation of intellectual disability to correctly assist in the diagnostic assessment.

During the assessment of intellectual disability, associated health conditions, co-morbidities, behavioural problems, psychiatric symptoms and psychiatric disorders are observed and diagnosed.

### **2.2.6 Associated health conditions and co-morbidities**

There is an increased risk of a number of congenital physical malformations and neurodevelopmental disabilities in people with intellectual disability (Nichol & Adnams, 2016:537). They may develop chronic primary and secondary medical

problems that occur more commonly than in the general population (as shown in Table 3). Certain genetic syndromes may also have clinical features or health conditions as part of the phenotype (as shown in Table 4) (Nichol & Adnams, 2016:537).

It is important to take cognisance of the information shown in Table 2 and Table 3 regarding the chronic health conditions associated with intellectual disabilities and the physical manifestations and clinical features of specific genetic syndromes respectively. These associated health conditions and co-morbidities can further complicate the management of intellectual disability.

Thompson, Kerr, Glynn and Linehan (2014:856) report that there is an “increased prevalence of epilepsy among those with intellectual disability when compared with the general population.” Thompson et al. (2014:856) further state that epilepsy carries a significant burden for families caring for an adult child with intellectual disabilities because it is typically severe in presentation. It is the most frequently reported co-morbidity, refractory to treatment and “it is incrementally more prevalent and complex among those who have more severe levels of intellectual disability.”

**Table 2: Chronic health system conditions associated with intellectual disability**

<b>Central nervous system or neurological</b>	- Epilepsy
<b>Oro-dental</b>	- Dental caries - Gum disease - Bony, facial and palate abnormalities - Swallowing incoordination
<b>Sensory</b>	- Visual problems - Hearing problems
<b>Cardiovascular</b>	- Congenital heart disease - Ischaemic heart disease
<b>Musculo- skeletal</b>	- Skeletal (especially spine) and joint deformities - Postural abnormalities - Muscle tone and power - Osteoporosis
<b>Gastrointestinal</b>	- Constipation - Gastro-oesophageal reflux disease - Upper gastrointestinal cancer

<b>Urinary tract</b>	<ul style="list-style-type: none"> <li>- Enuresis</li> <li>- Urinary retention</li> <li>- Urinary tract infections</li> </ul>
<b>Respiratory</b>	<ul style="list-style-type: none"> <li>- Upper and lower respiratory tract infections</li> </ul>
<b>Endocrine</b>	<ul style="list-style-type: none"> <li>- Type I and type II diabetes mellitus</li> <li>- Obesity</li> <li>- Hypothyroidism</li> <li>- Metabolic syndrome</li> </ul>
<b>Multiple system disorders</b>	<ul style="list-style-type: none"> <li>- Cerebral palsy</li> <li>- Ageing problems</li> </ul>
<b>Mental health</b>	<ul style="list-style-type: none"> <li>- Behavioural problems</li> <li>- Mental health problems</li> </ul>

Source: Adopted from Nichol & Adnams (2016:537)

Table 2 explores the chronic health conditions that can occur in the central nervous system or neurologically in a person with intellectual disability such as epilepsy, hearing problems, osteoporosis, constipation, enuresis, diabetes mellitus, cerebral palsy, behavioural problems and mental health problems. In the next section, behavioural problems and mental health problems are discussed in more detail.

### **2.2.7 Associated behavioural and psychiatric symptoms and psychiatric disorders**

In this section, the causes of challenging behaviour are discussed, and the associated psychiatric symptoms and psychiatric disorders in people with intellectual disability, are explored.

#### **2.2.7.1 Challenging behaviour**

The most common form of mental disorder in children and adults with an intellectual disability, and often the reason for presenting to mental health and related services, is challenging behaviour or problem behaviour (Nichol & Adnams, 2016:539).

The causes of challenging behaviour are complex and multifactorial and include medical, other co-morbid psychotic conditions and environmental factors (Nichol & Adnams, 2016:539,540). The following are the causes of challenging behaviour:

- **Medical factors**
  - Unrecognised pain or discomfort
  - Side effects of medication
  - Substance abuse
  - Physical illness (e.g. epilepsy)
  - Behavioural phenotypes – specific to a syndrome
  
- **Other co-morbid psychiatric conditions**
  - Attention deficit hyperactivity disorder (ADHD)
  - Depressive disorders and suicidal behaviour
  - Autism spectrum disorders (ASD)
  - Oppositional defiant disorder (ODD)
  - Conduct disorder (CD)
  - Anxiety disorders
  
- **Environmental factors**
  - Problems in the living and working environment
  - Life events (e.g. change of school, death, separation or returning to a residential facility after being home for a short period)
  - Communication problems (e.g. inability to communicate needs or emotions effectively, caregivers maladjusted to needs of the person with an intellectual disability, inappropriate response and management that reinforces challenging behaviour)
  - Life stage (e.g. puberty)
  - Challenging behaviour (e.g. behaviour serves a function or purpose for the person with an intellectual disability: challenging behaviour is maintained if the person is successful in altering their internal or external environment through their behaviour)

Nichol and Adnams (2016:539,540) discuss three types of behaviour, namely: aggression, self-mutilation/self-harm and inappropriate sexual behaviour:

- **Aggression**

People with intellectual disability may display aggressive behaviour, which may be unpredictable and unprovoked towards family members, peers, caregivers or health workers due to reduced frustration tolerance and disinhibited behaviour (Nichol & Adnams, 2016:539). They can sometimes become destructive, for example, damage personal objects and break windows. The reason for the behaviour may lie in the inability to verbalise pain and therefore a physical examination needs to be done to exclude fractures and infections (Nichol & Adnams, 2016:539).

- **Self-mutilation or self-harm**

People with intellectual disability may direct aggression towards themselves in the form of self-injury such as ingestion of objects or chemicals, self-biting, continuous scratching of a painful self-induced physical wound and head banging (Nichol & Adnams, 2016:539).

- **Inappropriate sexual behaviour**

People with intellectual disability may exhibit inappropriate sexualised behaviour such as inappropriate sexual fondling of peers or caregivers, imitating or performing acts of coitus and masturbating in public (Nichol & Adnams, 2016:540).

#### **2.2.7.2 Behaviour modification**

Behavioural problems must be approached on an individual basis and must be aimed at rewarding desirable behaviours and analysing the function of the undesirable behaviour for the adult child (Molteno, 2007:529). The following behaviour modification strategies can be used (Molteno, 2007:529):

- **Time out:** The adult child is removed from the reinforcing situation. The method must be instituted every time a specific behaviour occurs. The period of isolation should be brief and when released from timeout, the adult child is given a simple and unemotional explanation as to why it was used.

- **Restitution:** This involves rectifying the damage the adult child has caused. The restitution task must be within the capabilities of the adult child and must never be degrading. It should indicate to the adult child the consequences of the behaviour and that the behaviour has a negative reinforcing effect.
- **Medication:** This may be useful as an adjunct to other behavioural interventions. It should follow a full evaluation undertaken by a specialist in a secondary healthcare setting.

Social Workers can implement behaviour modification programmes with the adult children and this can be one of the strategies for social work interventions that can broadly promote the well-being of parents of adult children with intellectual disabilities.

### 2.2.7.3 Co-morbid psychiatric conditions

The entire spectrum of psychiatric disorders described in the general population manifest in people with an intellectual disability but they are also more susceptible to developing co-morbid psychiatric conditions than those with a normal intelligence (Nichol & Adnams, 2016:540).

Table 3 illustrates the genetic syndromes that people with intellectual disabilities can develop such as physical manifestations which include congenital cardiac defects and Alzheimer’s type dementia in adults.

**Table 3: Physical manifestations and clinical features of specific genetic syndromes**

Syndrome	Physical manifestations
<b>Cornelia de Lange</b>	<ul style="list-style-type: none"> <li>- Gastrointestinal disturbances – painful reflux</li> <li>- Hearing impairments</li> </ul>
<b>Prader- Willi</b>	<ul style="list-style-type: none"> <li>- Hyperphagia (presents in childhood)</li> <li>- Childhood and adulthood obesity</li> <li>- Diabetes mellitus</li> </ul>
<b>Tuberous sclerosis complex</b>	<ul style="list-style-type: none"> <li>- Epilepsy</li> <li>- Abnormal growths in multiple organs (e.g. brain tumours with headaches, double vision, dizziness)</li> </ul>

Syndrome	Physical manifestations
<b>Down</b>	<ul style="list-style-type: none"> <li>- Congenital cardiac defects (childhood and adulthood)</li> <li>- Hypothyroidism (childhood and adulthood)</li> <li>- Premature menopause</li> <li>- Alzheimer's- type dementia in adults</li> </ul>
<b>Williams</b>	<ul style="list-style-type: none"> <li>- Congenital cardiac defects (mostly present in childhood)</li> <li>- Heightened response to auditory stimuli</li> </ul>
<b>Angelman</b>	<ul style="list-style-type: none"> <li>- Epilepsy</li> </ul>
<b>Smith-Magenis</b>	<ul style="list-style-type: none"> <li>- Hearing impairments</li> </ul>

Source: Adopted from Nichol & Adnams (2016:538)

In the next section, the management of intellectual disability is explored, in order to address the challenging behaviour and associated health conditions and co-morbidities.

### 2.2.8 Management of intellectual disability

Table 4 shows that managing an intellectual disability requires a holistic approach, namely a biopsychosocial approach (Molteno, 2007:533). In the present study, the challenges of parents caring for adult children with intellectual disabilities were explored and described from a biopsychosocial approach.

**Table 4: Management of intellectual disability**

PHYSICAL (BIOLOGICAL)	PSYCHOLOGICAL	SOCIAL
<ul style="list-style-type: none"> <li>~ Treat reversible elements of the disability</li> <li>~ Treat associated medical conditions</li> <li>~ Prevent complications</li> <li>~ Symptomatic pharmacological control of difficult behaviour such as haloperidol</li> </ul>	<ul style="list-style-type: none"> <li>~ Attend to emotional needs of the patient and family</li> <li>~ Treat associated psychiatric disorders</li> <li>~ Education and support of family and caregivers</li> <li>~ Behaviour modification of difficult behaviours</li> </ul>	<ul style="list-style-type: none"> <li>~ Aim to maintain within the family or in the community. If this fails, implement foster care, residential placement or hospitalisation, as a last resort</li> <li>~ Day centres</li> <li>~ Occupational therapy</li> <li>~ Practical support to family</li> <li>~ Planning ahead in care of the parents death</li> </ul>

Source: Adopted from Molteno (2007:533)

Identification of how to manage intellectual disability in terms of biological, psychological and social factors (as shown in Table 4) may assist in devising strategies for social work interventions that can broadly promote the well-being of

parents of adult children with intellectual disabilities. This offers a holistic approach (a biopsychosocial model) when working with people and their families because problems in one area affect the other areas of the biopsychosocial model. Table 4 mentions the need for pharmacological treatment, attending to the emotional needs of both parents and their children and the importance of planning ahead when managing intellectual disability.

In order to effectively manage intellectual disabilities, it is important to explore the psychosocial implications for parents with adult children with intellectual disabilities in the family, the psychosocial implications of an adult child with intellectual disabilities in the care of parents as well as the effects on sibling relationships with adult children with intellectual disabilities.

### **2.3 THE PSYCHOSOCIAL IMPLICATIONS FOR PARENTS WITH ADULT CHILDREN WITH INTELLECTUAL DISABILITIES IN THE FAMILY**

Parents of adult children with intellectual disabilities often provide ongoing support until they no longer have the capacity to continue. They face many biopsychosocial challenges in coping with the long-term care of their children, which takes a progressive toll on their health and psychological well-being (Song et al., 2014:122).

Extensive evidence shows that mothers - and to a much lesser extent fathers - are more likely to show signs of psychological distress and experience lower levels of well-being than parents of "typically developing" children (Einfeld & Emerson, 2008:823). Einfeld and Emerson (2008:823) further mention that in addition to the health burden imposed on these parents, there is a link between adverse outcomes for children and distress among mothers. These outcomes include antisocial behaviour, failure to engage with services, decisions to seek out-of-home care for their child, impeded child development, less-than-optimal parenting and higher rates of child psychopathology.

Song et al. (2014:131) report that there is evidence that shows that the physical health of parents of adult children with intellectual disabilities is more susceptible to

the adverse influence of the lack of a flexible work schedule and to the spill-over of stress from work to family life than parents of adult children without disabilities.

When children with intellectual disabilities become adults, their parents are faced with a new set of challenges that accompany the aging process (Hasman & Zafron, 2010:34). Parents who are in the midlife phase of their life cycle go through a process of making decisions about their own futures and look forward to a less pressured life once their children become independent and leave home (Garcia-Preto & Blacker, 2014:241). However, this is not the case with parents of adult children with intellectual disabilities. Malepe (2015) and Raphokwane (2015) state that parents who are middle aged or elderly are in need of care and support themselves but they find themselves still providing care and support to their adult children with intellectual disabilities. Some of the challenges faced by these parents are lack of physical support in terms of resources in the community. Challenges also include the lack of emotional support as a result of not being able to have a social life, seeing their adult children as a burden and encounter financial difficulties when only one parent is working and therefore do not have sufficient financial resources to travel to the hospital and are unable to pay day care facilities (Malepe, 2015; Raphokwane, 2015).

A study by Pulusa (2006: 69) mentions that “families could not manage to satisfy the financial needs of their [children with an intellectual disability] and of the family as a whole.” Another challenge mentioned by Malepe (2015) is that some parents do not make plans for the time after their death. Dillenburger and McKerr (2010:30) propose that the thought of “what will happen when we become unable to care for our child ourselves?” is a stressful question faced by older parents of adult children with intellectual disabilities. The present study was motivated by this question in order to assist families in planning for their children’s future when they are no longer able to care for them.

Dillenburger and McKerr (2010:33, 34) suggested that the greatest challenges faced by older parents were their adult children’s care requirement, the need to keep them occupied, difficulties in dealing with behavioural problems, general supervision, medical care, future planning and their own health and well-being.

Parents of adult children with intellectual disabilities continue to provide care into their own old age because of a sense of parental responsibility as well as belief that there are no alternatives or that alternatives are unacceptable (Cuskelly, 2006:20). Another reason reported by parents is the mutual benefits to their situation, which includes receiving emotional support, assistance with household tasks and companionship. Parents also identified personal benefits from their caring role such as improved family relationships and personal growth (Cuskelly, 2006:20).

The reaction of families to children with intellectual disabilities is partly determined by the parents' thought process regarding their child, with specific regards to mothers with a high sense of control (Einfeld & Emerson, 2008:823).

Song et al. (2014: 132) mention that professionals are increasingly realising the benefits of psycho-education to help parents with adult children with intellectual disabilities to learn about the condition and strategies to cope with their child's behaviour problems and needs for assistance. In the present study, strategies were devised for social work intervention, which includes psycho-education to parents of adult children with intellectual disabilities that can broadly promote their well-being.

The present study also explored and described the challenges of parents caring for adult children with intellectual disabilities from a biopsychosocial perspective.

## **2.4 THE EFFECTS ON SIBLING RELATIONSHIPS WITH ADULT CHILDREN WITH INTELLECTUAL DISABILITY**

Sibling relationships are the most long-lasting and enduring relationship an individual develops during their lifespan (Doody, Hastings, O'Neill & Grey, 2009:224). However, some sibling relationships might be assumed to be more challenging because they involve individuals with intellectual disabilities (Doody et al., 2009:225).

Rossetti and Hall (2015:120) mention that "sibling relationships that involve an individual with intellectual disabilities are similar to sibling relationships between those without disabilities but may include a variety of unique interactions and circumstances that affect the nature of the relationship."

Having a brother or sister with an intellectual disability brings both challenges and rewards (Mulroy, Robertson, Aiberti, Leonard & Bower, 2008:225). A study by Rossiter and Sharpe (2001) found that there are some negative effects on a sibling's psychological development as a result of having a brother or sister with an intellectual disability (Rossetti & Hall, 2015:121). However, Mulroy et al. (2008:227) report that growing up with a sibling with an intellectual disability provides an experience for "character building" that is not available to their peers. Close personal relationships and psychological benefits were also reported by adult siblings of individuals with intellectual disabilities and female siblings experience higher levels of volunteerism and exposure in helping professions (Rossetti & Hall, 2015:121).

As parents age, there may be involvement of renegotiation of roles within the family in an effort to secure ongoing support and care for the adult child with intellectual disabilities (Coyle, Kramer & Mutchler, 2014:303). Therefore, most parents prefer and expect that a sibling will assume these responsibilities once the parents are no longer able to provide care (Coyle et al., 2014:303). It becomes vital for siblings as the new caregivers to have access to reliable resources to assist them with their increased responsibilities (Hasman & Zafron, 2010:34).

Even though the present study focused on the challenges of parents caring for adult children with intellectual disabilities, it can be expected that siblings might experience similar challenges if they become the primary caregiver once their parents are no longer able to provide care. Therefore, social work interventions that can broadly promote the well-being of parents and can also benefit the siblings of adult children with intellectual disabilities. Further research should be conducted on the challenges these siblings experience once they start providing care to their adult sibling with intellectual disabilities.

## **2.5 THE IMPLICATION OF AN ADULT CHILD WITH INTELLECTUAL DISABILITIES IN THE CARE OF PARENTS**

The needs of people with intellectual disabilities and of their family change as the person develops and ages (Bentley & Molteno, 2015:605). Nadioo (2006:173) mentions that Erikson (1959) developed eight stages of psychosocial development.

The adult children in the present study will fit into stages 6 and 7. In stage 6 – intimacy vs. isolation – young adults aged between 18 and 40 years begin to share themselves more intimately with others and explore relationships leading towards longer-term commitments with someone other than a family member (Nadivoo, 2006:173). In stage 7 – generativity vs. stagnation – middle aged adults between the ages of 40 and 65 years establish their careers, settle down within a relationship, begin their own families and develop a sense of being a part of the bigger picture (Nadivoo, 2006:173). Adult children with intellectual disabilities are significantly less likely than their non-disabled peers to move out of their family home, have friends, be employed, have long-term intimate relationships and participate in the life of their communities (Einfeld & Emerson, 2008:823).

Bentley and Molteno (2015:608) report that people with all levels of intellectual disability may experience sexual desires and sexual pleasure. It is important to educate and create awareness regarding sex in order to prevent abuse of the adult children with intellectual disabilities but also to prevent them from abusing other younger and vulnerable children.

Adult children with intellectual disabilities have the same needs and desires as everyone else and therefore their rights regarding sexuality such as the right to be treated with respect and dignity, the right to know about their bodies and those of others, the right to be sexual – to make and break relationships and the right not to be sexually abused or to be at the mercy of sexual attitudes of individual caregivers, should be emphasised at all times (Molteno, 2007:532). There is often a perception that adult children with intellectual disability have the cognitive capacity of a five-year old and that their sexual awareness and emotional needs will also be at this level. This is however seldom the case (Bentley & Molteno, 2015:608). Parental attitudes to sexuality require modification because they can adversely affect adult children with intellectual disability (Molteno, 2007:532). With support, education and counselling, adult children can be helped towards a better understanding of themselves and of others (Molteno, 2007:532).

In the researcher's opinion, it is important to create awareness amongst children as well as adult children with intellectual disabilities regarding personal boundaries in terms of "good/bad" touch. It is pivotal to provide education regarding their bodies

and those of others as well as the different types of abuse to ensure a better quality of life. In the Indian community - as in many other communities - the discussion of sex or any sexual activity is frowned upon and pre-marital sex is taboo. Therefore, it is more difficult to create sexual awareness for people with intellectual disabilities who are capable of seeking sexual pleasure.

Malepe (2015) and Raphokwane (2015) also mention that most of these parents treat their adult children like small children who do not have their own needs and wants. As a result, due to lack of exposure to the outside environment, some adults with intellectual disabilities end up putting on weight, abusing their siblings physically and sexually and committing crimes in the community.

Adult children with intellectual disabilities are more likely to experience poor general health and have a decreased life expectancy (Einfeld & Emerson, 2008:826). This can be attributed to the quality of existing health care support provided to people with intellectual disabilities, behavioural or lifestyle factors, increased risk to exposure to socio-economic disadvantage and the impact of the underlying genetic or biological causal factors of intellectual disability on their health.

Young adults with intellectual disability demonstrate lower levels of physical activity, experiences higher rates of obesity and are at greater risk for additional secondary health conditions and therefore the promotion of physical activity to this population is of a particular need (Pitchford, Siebert, Hamm & Yun, 2016:25). Physical activity should be part of the school curriculum to encourage healthy lifestyles especially among those with intellectual disabilities. Community involvement can promote physical activity amongst people with intellectual disabilities by actively involving them in fun walks and creating more parks that are accessible.

Pitchford et al. (2016:25) suggest that “parents play an essential role in the reinforcement of physical activity for their child, which has direct and indirect influences on their child’s physical activity behaviour.” However, these children could experience limited exposure to physical activity if their parents are overprotective (Pitchford et al., 2016:26).

For an adult child with intellectual disabilities, a fulfilling adult life is associated with productive vocational and educational activities (Taylor & Hodapp, 2012:67).

However, many of them do not have such regular daytime activities. Ideally, every adult child regardless of the level of severity of their intellectual disability should be able to attend a day care centre in order to take part in some form of vocational and educational activity. This also means that more day care centres should be established that accommodates all the different levels of severity of the intellectual disability.

People with intellectual disabilities may be at a greater risk of experiencing stress and also more likely to have fewer resources available to help them to cope with that stress (Scott & Havercamp, 2014:552). They may experience less control over both minor daily life decisions (such as what to eat for lunch) and major life decisions (such as where they will live). This has shown to increase the impact of stressors on people with intellectual disabilities (Scott & Havercamp, 2014:552). People with intellectual disabilities should be included in every decision made regarding their life, no matter how small to ensure that their rights and dignity are always respected.

In the past people with intellectual disabilities, had more opportunities to live in a group or institutional setting but presently, family members are increasingly expected to be the primary caregivers. Parents of adult children with an intellectual disability are likely to provide continuing care to their children well into old age and this aging process has its own set of unique challenges (Cuskelly, 2006:24; Hasman & Zafron, 2010:34). However, one of the main predictors whether parents seek a residential placement for their child is problematic or “challenging” behaviour (Einfeld & Emerson, 2008:823).

With the move away from institutional care there is a need for group homes in the community to take over the care as parents’ age, especially if there are no siblings available to continue the care of the person with intellectual disability (Bentley & Molteno, 2015:607). Therefore, the principles of community living such as physical presence in the community, health, safety and basic comfort, social relationships, personal autonomy and choice, opportunity for personal growth and valued community participation whether the person remains with the family or in a group home is an important part of community involvement (Bentley & Molteno, 2015:607).

The principles of community living ensure the active involvement of people with intellectual disabilities in the community and address their right to be included.

The participants in the present study belong to the Indian community and therefore it is important to explore the role of culture in caring for their adult children.

## **2.6 THE ROLE OF CULTURE IN CARING FOR ADULT CHILDREN WITH INTELLECTUAL DISABILITIES IN THE INDIAN COMMUNITY**

People's way of living is determined by their culture (Moleko, 2012:163) and therefore the present study explores the role that culture plays in caring for adult children with intellectual disabilities in the Indian community with specific regards to their cultural values, norms and belief system. Culture is described as "the attitudes, behaviour and traditions a certain group of people abide by, and these characteristics are passed on from one generation to the next" (Moleko, 2012:164). Semanya and Mokwena (2012:72) define culture as "the ways in which different societies understand their collective systems of meaning and meaning making, as well as their collective ways of valuing and understanding the world which they inhabit." Culture also influences a person's thoughts, behaviour, emotional expressions, experiences and other general areas of functioning (Moleko, 2012:163).

Cultural norms determine the thresholds between health and disease and therefore shared meanings, values and traditions influence both vulnerability and resilience to illness, how support is accessed and received, liability to stigma and other forms of social disadvantage, and illness duration and outcome (Smith, 2015:126,127). Semanya and Mokwena (2012:79) mention that the "focus is not only on the disease, but also on understanding the individual embodying the disease, and the community or environment within which the individual lives" and therefore, in order to understand a person's illness, their environment, which consists of inanimate objects, animals and plants, human, ancestral spirits and God, needs to be understood (Semanya & Mokwena, 2012: 75, 79).

People hold a range of beliefs about illness and distress and when an illness occurs people often first turn for advice to their neighbours and relatives and people in their communities who are not necessarily seen as 'healers' but who are trusted people whom are also close by (Swartz, 2015:40).

Different cultures view health in different ways, for example: traditional Chinese medicine health is seen as a balance between yin and yang, or the 'hot' and 'cold' qualities of an individual. In the ancient Indian system of medicine (Ayurveda), health is viewed as a harmony between body, sense organs, mind and world, where in Western medicine, health is mainly seen as an absence of disease, with a focus on the biological aspects of life (Baxter & Mahoney, 2016).

Approaches to disability are also influenced by culture. They include the understanding of a disability and its aetiology, the decision of whether to seek help, choice of treatment options and relationships with health professionals (Baxter & Mahoney, 2016).

In many cultures attitudes towards a disability may include religious acceptance, belief that a disability is caused by factors such as the influence of 'past lives', mystical interventions or the past actions of a parent and therefore people may seek out spiritual healers and traditional 'alternative' medicine (Baxter & Mahoney, 2016). Indian families may combine yoga, Ayurveda and homeopathy with conventional medicine (Baxter & Mahoney, 2016).

Different cultures have different views of disability and treat children with intellectual disabilities in different ways and therefore it is common that 'blame' for a disability may be placed on the mother or both parents, or the child's condition may be considered an "act of God" (Baxter & Mahoney, 2016).

People with an intellectual disability who are from culturally diverse backgrounds will experience intense multiple forms of discrimination throughout their lives due to the following reasons (Intellectual disability and people...[sa] ):

- A person with an intellectual disability may experience discrimination or shame within their cultural group because of their disability,
- A person may experience separation from their family of origin due to institutionalisation or removal from his/her family due to abuse or neglect, and,
- A person with an intellectual disability may receive support from a service or organisation and that service may not provide the support required for the person to participate fully in their culture and its traditions.

A study conducted by Gabel (2004) involving first-wave North Indian Hindu immigrants residing in the USA reported three dominant beliefs about people with intellectual disabilities (Sheridan & Scior, 2013:1241):

- The belief in consequences of bad deeds such “Karma and Punarjanamphala”, which reflects the Indian Hindu belief in reincarnation and regards any disability as a result of bad deeds from a previous life.
- The idea of “suffering through” so that a person must endure disability without complaint (acceptance) is regarded as a welcomed opportunity for enlightenment that could free oneself from the cycles of death and rebirths.
- Mundh Buddhi, is a concept that promotes the idea that a person with an intellectual disability is able to do the same things and at the same pace as people without intellectual disability, but chooses not to due to laziness.

A study by Sheridan and Scior (2013:1246) echoes earlier studies regarding the attitudes of Indians towards intellectual disability which include fatalism, the search for a cure, the stigma of bearing a child with a disability and fears about the potential negative impact on the marriage prospects of siblings.

After identifying the psychosocial implications for parents with adult children with intellectual disabilities, it is important to explore the policies and legislation regarding intellectual disability to address the challenges experienced by these parents and their children.

## **2.7 POLICIES AND LEGISLATION REGARDING INTELLECTUAL DISABILITY**

In South African, there are more policies that address disabilities - including intellectual disability - than in other African countries (Adnams, 2010:439). The South African Constitution and the Mental Health Care Act makes provision for people with disability and addresses the rights of mental health care users, including users with intellectual disabilities (Adnams, 2010:439). In recent years, there has been an increase in the quality of life and life expectancy of those with an intellectual disability largely due to improved intervention of health disorders driven by increased

recognition of the rights of people with disabilities to have health care (Nichol & Adnams, 2016:538).

As stated by the Department of Social Development (DSD,[sa]:28, 29), there are three main programmes in which disability is addressed, namely: social security programmes (disability grants), social welfare programmes (focusing on the provision of developmental social welfare services) and community development programmes (focusing on enhancing and increasing the capacity of communities to respond to their own needs and improve their capacity for development).

The core services of the Department of Social Development focus on meeting the needs of people with disabilities and building on their strengths as well as the strengths of their families, communities and other social groups and support networks are (DSD,[sa]:29).

The following are the core services provided by the Department of Social Development (DSD,[sa]:29):

- Rehabilitation services
- Social Security
- Capacity and Empowerment Programmes
- HIV & Aids Services
- Promoting Sustainable Livelihoods for People with Disabilities
- Promoting enhanced Social Integration to achieve Disability Equity
- Services to Child & Youth with Disabilities
- Residential Facilities for People with Disabilities
- Support services to Family
- Development programmes for Women with Disabilities
- Victim Empowerment
- Services to Older People with Disabilities

The National Disability Rights Policy “will update the White Paper on an Integrated National Disability Strategy (INDS), and will integrate the obligations contained in the

UN Convention on the Rights of Persons with Disabilities (UNCRPD)” (DSD, 2015:10).

The National Disability Rights Policy places equal responsibility for changing the lives of persons with disabilities on the duty bearers (i.e. a person who has the responsibility to respect, promote and realise the human rights) and the rights of holders (i.e. a person who has exclusive rights to the mentioned policy) by (DSD, 2015:10):

- Taking action to ensure that their rights as equal citizens are upheld,
- Removing discriminatory barriers to access and participation,
- Ensuring that universal design access informs the planning, budgeting and service delivery value chain,
- Recognising the right to self-representation,
- Acknowledging that not all persons with disabilities are alike, and that personal circumstances, gender, age, sexuality, cultural backgrounds, geographical location, requires different responses, and
- Embedding the obligations contained in the UN Convention on the Rights of Persons with Disabilities in legislation, policy and service delivery.

By identifying the challenges of parents caring for adult children with intellectual disabilities, the present study aims to address the gaps in the implementation of policies in the community. In the present study, participants that accessed services at the Laudium Mental Health Society were selected. The Laudium Mental Health Society is affiliated to the South African Federation for Mental Health, which is a non-governmental organisation that advocates for the human rights of people with intellectual disabilities, amongst other issues. By identifying the challenges that Indian parents face when caring for their adult children with intellectual disabilities, the researcher envisages that the South African Federation for Mental Health can assist in fulfilling the gaps in the implementation of policies, which can benefit the Indian community by advocating human rights issues and establishing an improvement in service delivery.

The researcher agrees with Adnams (2010:436) that “despite the existence of policies and services for the population with intellectual disabilities in South Africa, recognition of and provision for their needs carries low priority.”

One of the roles of Social Workers is to advocate for the rights of vulnerable groups such as people with intellectual disabilities and therefore the next section will explore the role of Social Workers in assisting parents with adult children with intellectual disabilities.

## **2.8 THE ROLE OF SOCIAL WORKERS IN ASSISTING PARENTS WITH ADULT CHILDREN WITH INTELLECTUAL DISABILITIES**

Social Workers play an important role in meeting the needs of people with intellectual disabilities because they provide assessment, intervention and advocacy for people with intellectual disabilities and their families (Robinson et al., 2012:176). Social Workers who work with people with intellectual disabilities and their families, are presented with challenges because they often do not have sufficient skills and knowledge to provide appropriate interventions due to lack of awareness, research and formal education (Robinson et al., 2012:176). Therefore, by exploring and describing the biopsychosocial challenges of parents caring for adult children with intellectual disabilities, the present study is making suitable recommendations for social work interventions that can broadly promote the well-being of parents of adult children with intellectual disabilities and potentially contribute towards filling the research gap.

There are three key areas of social work that were identified as early as 1913, which do not seem to have changed since (Bigby & Atkinson, 2010:6). They include support of people with intellectual disabilities and their families, acting as the “go-between” linking the institution with the community and working directly with people already in the community to enable them to lead “ordinary lives”. Working with complex clients such as adults with intellectual disabilities and their parents places Social Workers in important roles to support and empower their clients to engage in care when faced with challenging circumstances (Findley, 2014:84).

Providing support is a pivotal role played by Social Workers. By exploring and describing the biopsychosocial challenges, the present study will make recommendations, from a biopsychosocial approach, for Social Workers that will provide support to parents caring for adult children with intellectual disabilities.

There are four key areas of social support that are experienced by caregivers (Cameron and Gignac, 2007:309). The support in these areas can be provided by the Social Worker. The first type is informational support; which includes functional levels of intellectual disability, social and health impact of intellectual disability, causes of intellectual disability and treatment options. This type of support can be based on the biological challenges. The second type of support; emotional support is aimed at helping people, especially parents, to reduce feelings of distress and upset. This type of support can be based on the psychological challenges. The third type of support; instrumental support, can include help with tasks and planning or training to improve caregiver's management of care. The fourth type of support, appraisal support, includes "feedback or an evaluation of caregiver efforts in order to validate their experiences and to help improve their care giving abilities" (Cameron & Gignac, 2007:309). The third and fourth type of support can be based on the social challenges.

## **2.9 SUMMARY**

In this literature review section, challenges of parents caring for adult children with intellectual disabilities are explored and explained providing an overview about intellectual disability and discussing the psychosocial implications for parents with adult children with intellectual disabilities in the family, the implications of an adult child with an intellectual disability in the care of parents as well as the influences on sibling relationships with adult children with intellectual disabilities. This section also includes policies and legislation related to intellectual disability, the role of culture in caring for adult children with intellectual disabilities in the Indian community and the role of the Social Worker in assisting parents caring for adult children with intellectual disabilities.

Intellectual disability is a lifelong condition, affecting the person as well as the family at every life stage. Associated health conditions, behavioural problems and co-morbidities further complicate the management of intellectual disabilities resulting in challenges for parents and siblings caring for adult children with intellectual disabilities. The present study focuses on the challenges of Indian parents and explores the role of culture and cultural views of intellectual disabilities, within the Indian community, and how these contribute to their understanding of the causes of intellectual disability.

Families are unique in their personalities, structures, dynamics and propensity for adaptation. Challenges faced by families can be alleviated rather than exacerbated by listening to families, working and building better relationships with them and meeting their needs (Chadwick, Mannan, Iriarte, McConkey, O'Brien, Finlay, Lawlor & Harrington, 2012:130). Chadwick et al. (2012:130) further mention that service providers, policy makers and the wider community "should work more closely with families to address these needs to enable people with intellectual disabilities and their families to feel supported, empowered, included and afforded their basic human rights."

The future of people with intellectual disabilities in southern Africa depends on how the following issues are addressed (Molteno, 2007:532):

- Many causes are preventable and such conditions should be targeted for prevention strategies.
- There needs to be a shift in focus towards community-based care and this involves the need for equity in service provision in both rural and disadvantaged communities.
- The public should be enlightened regarding the various aspects of disability so that resources may be made available to meet the needs of affected people.

There is a huge research gap regarding the challenges of Indian parents caring for an adult child with intellectual disabilities and there are also limited resources on this topic in South Africa. The present study aims to address the research gap by identifying the challenges, so that services and programmes can be developed and

implemented to enhance service delivery and to ensure a better quality of life for both the adult child and their family.

The next chapter, Chapter 3, discusses the research methodology and empirical findings.

## CHAPTER THREE

### RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

#### 3.1 INTRODUCTION

This chapter focuses on the research methodology applied in the present study and the presentation of empirical results. The present study was guided by the following research question:

**“What are the challenges of Indian parents caring for adult children with intellectual disabilities?”**

The research methodology and ethical aspects of the present study will be presented first, followed by the empirical findings of the present study.

#### 3.2 RESEARCH APPROACH

A qualitative research approach was used for the present study to explore the challenges of parents caring for adult children with intellectual disabilities by getting a detailed description of the situation as to understand the situation better.

Qualitative research uses words as data, while quantitative research uses numbers as data (Braun & Clarke, 2013:3, 4). The qualitative approach is more suitable when the researcher is trying to understand the meaning people attach to situations because it allows for a much richer or deeper understanding of a phenomenon than could be achieved by using numbers (Braun & Clarke, 2013:24). Durrheim (2006:47) expands on this and highlights that in a qualitative approach data is collected “...in the form of written or spoken language or in the form of observations that are recorded in language, and analyse the data by identifying and categorising themes.” The qualitative approach can be used to explore, interpret and understand a subjective world and therefore a research question can guide the types of observations to be made, in order to understand a phenomenon (Du Plooy, 2009:35).

### **3.3 TYPE OF RESEARCH**

The category of applied research was used in the present study because the researcher wanted to explore and describe parents in the Indian community with regard to the challenges they face caring for adult children with intellectual disabilities.

Applied research is used when the researcher wants to assist in solving a particular problem that a particular community is facing (Bless, Higson-Smith & Sithole, 2013:59). Applied research aims to contribute towards practical issues of problem solving, decision making, policy analysis and community development (Durrheim, 2006:45, 46). By identifying the challenges faced by parents caring for adult children with intellectual disabilities, services can be developed and implemented to enhance their quality of life.

Exploratory research is used when the purpose of the research is to gain a broad understanding because limited knowledge or information exists about a specific situation, phenomenon or community (Bless et al., 2013:60). The present study was exploratory in nature because little is known about the challenges of parents caring for adult children with intellectual disabilities within the South African Indian community.

### **3.4 RESEARCH DESIGN**

The research design was a case study. A case study is an “in-depth examination of a single instance of some social phenomenon” (Babbie, 2011:301). The researcher wanted to study a group of individuals regarding the challenges they face caring for their adult children with intellectual disability. Therefore, the researcher used a collective case study (which is a type of case study). In this type of study, “the cases are individual narratives or units which share several common characteristics...” (Shkedi, 2005:21). In the present study, the researcher conducted interviews with Indian parents whose adult children have intellectual disabilities in order to explore the challenges they face.

## **3.5 RESEARCH METHODS**

### **3.5.1 Study population and sampling**

#### **3.5.1.1 Population**

A population refers to “the entire set of individuals or other entities to which study findings are to be generalized” (Engel & Schutt, 2013:112). The population of the present study consisted of Indian parents who have adult children with intellectual disabilities and who are accessing services at the Laudium Mental Health Society.

#### **3.5.1.2 Sampling method**

Non-probability sampling with specific regards to purposive and snowball sampling was used in the present study. In non-probability sampling, the researcher can rarely determine the sample size in advance as is the case in this study because the researcher does not know the population size or the members of population and has limited knowledge about the larger group or population from which the sample is taken (Neuman, 2012:167).

Purposive sampling is used to “get all possible cases that fit particular criteria, using various methods” and it is also most appropriate for exploring research because particular types of cases are identified for in-depth investigation (Neuman, 2012: 167, 169). Purposive sampling is used when the researchers “purposely seek typical and divergent data” (Strydom & Delpert, 2011:392). As the researcher could not acquire all the participants through the purposive sampling method, the snowball sampling method was also used. Strydom and Delpert (2011:393) mention that “snowball sampling has particular application value in qualitative research, since it is directed at the identification of hard-to-reach individuals.” Therefore, in snowballing, one participant is approached to identify another participant and this process is continued until data saturation has taken place (Strydom & Delpert, 2011:393).

To be included in the present study, the person had to meet the criteria listed below. The person had to be

- a South African citizen;

- an Indian, from any religion;
- father or a mother of an;
  - adult child or children (20 years and older), with an intellectual disability;
  - adult child who attends the day care centre at the Laudium Mental Health Society; and/or
- a parent who accessed services such as counselling/support at the Laudium Mental Health Society or whose child accessed these services.

### **3.5.1.3 Sample**

A sample refers to “a carefully selected group of cases that is intended to reflect the broader population from which it has been drawn” (Henn, Weinstein & Foard, 2009:337).

In the present study, the sample referred to the first 12 participants who meet the criteria of the present study.

### **3.5.1.4 Recruiting participants**

Potential participants need to be informed about the research through some form of advertising (Braun & Clarke, 2013:59). The present study was advertised at the Laudium Mental Health Society because they render services to adults with an intellectual disability and to their families. The method of advertising and contacting the potential participants was as follows:

- The study was discussed with the employees (Social Workers, Community Workers and Management) of the Laudium Mental Health Society where adult children with intellectual disabilities and their families access services.
- Based on the selection criteria, adult children and their parents accessing services at the Laudium Mental Health Society were informed about the intended study by the employees of the organisation. By completing the descriptive informational letter, participants provided their names and contact details to the employees.
- The researcher contacted the potential participants to schedule an appointment for the interviews.

- The researcher followed the selection process until the required numbers (12 participants) were reached or data saturation was reached should there be an insufficient number of participants.

### 3.5.2 Data collection

Data collection provides a detailed account of how the data will be collected (Van der Riet & Durrheim, 2006:85). The researcher used semi-structured interviewing to collect data in this study. A semi-structured one-to-one interview is “... a set of predetermined questions on an interview schedule...” (Greeff, 2011:352). An interview schedule is a questionnaire written to guide the interview because it consists of a broad range of themes or question areas to be covered in the interview (Greeff, 2011:352). By using this type of data-collection method, the researcher and participants will have more flexibility because the interview will be guided by the schedule rather than dictated by it. The researcher made use of a digital recorder, field notes and observations. The interviews were conducted in the participants’ homes or at a neutral venue such as an office once the participants signed informed consent. Once the participants signed the informed consent forms, the researcher began interviewing the participants using the interview schedule.

Table 5 shows the advantages and disadvantages of using semi-structured interviews (Keller & Conradin, [sa]):

**Table 5: Advantages and disadvantages using semi-structured interviews**

Advantages	Disadvantages
<ul style="list-style-type: none"> <li>• Many researchers prefer using semi-structured interviews because questions can be prepared ahead of time. This allows the interviewer to be prepared and appear competent during the interview.</li> <li>• Semi-structured interviews also allow informants the freedom to express their views in their own terms.</li> <li>• Semi-structured interviews can provide reliable, comparable qualitative data.</li> <li>• Semi-structured interviews encourage</li> </ul>	<ul style="list-style-type: none"> <li>• Interviewing skills are required.</li> <li>• Need to meet sufficient people in order to make general comparisons.</li> <li>• Preparation must be carefully planned so as not to make the questions prescriptive or leading.</li> <li>• Skills to analyse the data can be a problem – risk of construing too much.</li> <li>• Time consuming and resource intensive.</li> <li>• Confidentiality has to be ensured.</li> </ul>

Advantages	Disadvantages
<p>two-way communication. Those being interviewed can pose questions to the interviewer. In this way it can also function as an extension tool.</p> <ul style="list-style-type: none"> <li>• Confirms what is already known but also provides the opportunity for learning. Often the information obtained from semi-structured interviews will provide not just answers, but the reasons for the interviews.</li> <li>• When individuals are interviewed they may more easily discuss sensitive issues.</li> <li>• Help field staff become acquainted with community members. Outsiders may be better at interviewing because they are perceived as more objective.</li> <li>• Using both individual and group interviews can optimise the strengths of both.</li> </ul>	

The researcher mitigated the risks of the mentioned disadvantages in the following ways:

- 1) The researcher has 6 years experience as a Social Worker. She has conducted a research study as partial fulfilment of her BA (Social Work) degree and has extensive skills as an interviewer.
- 2) The researcher interviewed 12 participants in the present study to allow for a general comparison of the findings.
- 3) The interview schedule was well planned and researched, and therefore the questions were not prescriptive nor leading.
- 4) The researcher critically examined the information collected, together with the literature available on the themes and categories identified.

5) The researcher recruited 12 participants during the data gathering process; however, some participants withdrew their consent to participate which resulted in the researcher having to ask the active participants to refer other potential participants for the study. Therefore, in this way the researcher reduced the time and resources that would have been needed, otherwise this would have ended up being a very time consuming and resource intensive process.

6) In order to ensure confidentiality, the researcher made use of pseudonym and not the actual names of the participants.

### **3.5.3 Data analysis**

The aim of data analysis is to transform information or data, which provides an answer to the research question (Durrheim, 2006:52). Schurink, Fouché and De Vos (2011:403,404) identified eight key steps which are used as a guideline when conducting qualitative data analysis.

#### **3.5.3.1 Planning for recording of data**

The researcher planned for the recording of data in a systematic manner. The researcher used a digital recorder with the permission of the participants. The participants completed a letter of informed consent. These recorded interviews were later transcribed verbatim. The information collected was separated into digital recordings, transcripts of the interviews, process notes taken during the interview and field notes immediately after the interview.

#### **3.5.3.2 Data collection and preliminary analysis**

The information collected was separated into digital recordings and transcripts of the interviews, process notes taken during the interview and field notes immediately after the interview. The researcher did not foresee any gaps in the data collection because the interview schedule was well planned and researched.

### **3.5.3.3 Managing the data**

Once the interviewing process was completed, the researcher transcribed the interviews. The researcher gathered all the data by organising it in paper file folders and analysing the information according to themes and patterns. The information was then coded according to these themes and subthemes by marking the themes identified in the various texts in different colours. Backup copies of all the data were made.

### **3.5.3.4 Reading and writing memos**

Once the data was organised, the researcher read and reread the data gathered until she had a better understanding of it. The researcher also made notes alongside the margins of the data collected.

### **3.5.3.5 Generating categories and coding the data**

The researcher took the data gathered and looked for categories, themes or patterns in the information by using different colour highlighters, pens, abbreviations of keywords, coloured dots and numbers.

### **3.5.3.6 Testing the emergent understandings and searching for alternative explanations**

Once themes in the information was identified and coded, the researcher tested this understanding by considering other explanations of the information and deciding on the most likely explanation. This was done through critically examining the information collected together with the literature available on the themes and categories identified.

### **3.5.3.7 Interpreting and developing typologies**

The researcher interpreted the data according to the patterns, categories and themes by linking it to the relevant literature and theoretical framework.

### **3.5.3.8 Presenting the data**

The researcher made use of quotations from the data gathered as a way of providing evidence and to support the themes identified.

### **3.5.4 Trustworthiness**

Qualitative research should, as closely as possible, reflect the thoughts, feelings and experiences of those who participate in research (Lietz, Langer & Furman, 2006:444). The research results should reflect that we, as researchers, are hearing what our participants are saying (Lietz et al., 2006:444,456).

In quantitative research, reliability and validity refers to the research instrument and therefore the researcher is the data gathering instrument in qualitative research (Maree, 2007:80). Thus when qualitative researchers speak of research validity and reliability they are usually referring to research that is credible and trustworthy (Maree, 2007:80). There are four constructs that are used when assessing the quality of qualitative research namely credibility, transferability, dependability and conformability (Schurink et al., 2011: 419,420, 421).

#### **3.5.4.1 Credibility**

The goal of credibility is to “demonstrate that the inquiry was conducted in such a manner as to ensure that the subject has been accurately identified and described” (Schurink et al., 2011:419). The following strategies increase credibility in the study:

- **Peer debriefing**

The researcher works in a psychiatric institution and thus had many colleagues who work with individuals and their families with intellectual disabilities. The researcher discussed any difficulties experienced during the research process as well as the research findings with her colleagues and used them as a constant soundboard.

- **Member checking**

Once the interviews were completed and transcribed, the researcher clarified the information obtained with each participant to ensure the trustworthiness of the data.

#### **3.5.4.2 Transferability**

This was a qualitative study and therefore the findings could not be generalized because the participants are unique individuals who have different perspectives, experiences, attitudes and behaviours.

#### **3.5.4.3 Dependability**

The researcher planned for the recording of the data in a systematic manner and used one semi-structured interview schedule. The researcher used digital recordings for all interviews to ensure uniformity during data collection.

#### **3.5.4.4 Conformability**

- **Audit trail**

A note book was kept throughout the research process to document the steps taken in the data analysis. An audit trail allows the researcher to be flexible with the research procedures. Therefore an audit trail provides evidence that supports the research findings and the interpretations thereof.

- **Reflexivity**

Lietz, Langer and Furman (2006:447) mention that “reflexivity is the active acknowledgment by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation.” Therefore, the researcher made field notes during the interviews and afterwards reflected upon the impact which each interview and participant had on her. The researcher has not published these field notes for the present study.

### **3.5.5 Pilot study**

A pilot study is described by Fouché and Delpont (2011b:73) as “...a small-scale implementation of the planned investigation in an attempt to bring possible deficiencies to the fore timeously.”

Conducting research involves costs and it is therefore a good idea to conduct a pilot study before implementing the final research (Van der Riet & Durrheim, 2006:94). Pilot studies are preliminary studies on small samples that help to identify potential problems with the design (Van der Riet & Durrheim, 2006:94).

Assessing the feasibility of the study and testing the measuring instruments are the main purpose in conducting a pilot study (Fouché & Delpont, 2011b:73). A pilot study was conducted by using the first participant who met the criteria for the study.

## **3.6 ETHICAL CONSIDERATIONS**

Ethics is defined by Hornby (2010:500) as “moral principles that control or influence a person’s behaviour.” Therefore, the following ethical aspects must be taken into consideration:

### **3.6.1 Avoidance of harm**

The researcher should be aware of all types of potential harm, which include legal, physical, psychological harm as well harm to a person’s career, reputation or income and as a result take specific actions to minimize the risk to participants at all times (Neuman, 2012:71,72).

The purpose of the study did not intend to cause harm; however, the researcher realised that participants may feel vulnerable or experience discomfort in sharing personal information. The researcher created a safe and supportive environment in order to minimise discomfort. The participants were made aware, before participating in the study, what the role of the researcher was and that she will not offer social work intervention. Should participants require counselling or other specialised

services; the researcher would suggest a referral to a Social Worker rendering supportive services at the Laudium Mental Health Society.

### **3.6.2 Informed consent**

Participation must be voluntary at all times because “people need to know what they are being asked to participate in so that they can make an informed decision” (Neuman, 2012:75).

The researcher obtained informed consent from each participant in the study before the start of the interview. Informed consent was a written letter, explaining to each potential participant the nature, goal and procedures of the study. This provided potential participants with the necessary information about the study. The researcher highlighted the issues of confidentiality, anonymity and the fact that pseudonyms would be used in the transcripts and research report. Participants were also requested to give their permission for digital recordings of the interview and they were notified that these recordings would be stored at the University of Pretoria archives for 15 years after completion of the study. The researcher also informed the participants that they may withdraw from the study at any stage of the research process. Each participant was given a copy of the letter of informed consent.

### **3.6.3 Deception of subjects**

Corey, Corey and Callanan (1993:230), as mentioned in Strydom (2011:119), state that “deception involves withholding information, or offering incorrect information in order to ensure the participation of subjects when they would otherwise possibly have refused it.”

The researcher was aware of the consequences of deliberately withholding information or offering incorrect information in order to ensure participation of participants when they would have otherwise refused. Therefore, the researcher avoided deception at all times by informing the participants exactly what the research entailed at each stage of the research process.

### **3.6.4 Confidentiality**

Strydom (2011:119) emphasizes that “confidentiality can be viewed as a continuation of privacy, which refers to agreements between persons that limit others’ access to private information.” Data must not be released in such a way that identifies specific individual’s responses (Neuman, 2012:78).

Each participant was assured that every effort would be made by the researcher to safe-guard and maintain confidentiality. In the present study, a pseudonym and not the actual names of the participants were used.

### **3.6.5 Actions and competence of researchers**

Strydom (2011:124) highlights that researchers have an ethical obligation to ensure that they are adequately and competently skilled to undertake the study. The researcher is a qualified Social Worker and has conducted a research study as partial fulfilment of her BA (Social Work) degree. The researcher is registered with the South African Council for Social Service Professions (SACSSP) and has two years’ experience working with people with intellectual disabilities. The researcher was guided by her University of Pretoria (UP) supervisor during the present study. The researcher is aware of the implications of plagiarism and therefore referenced all sources within the text and in the reference list used in the study.

### **3.6.6 Release of publications or findings**

The importance of making the publication or findings public in a written form is highlighted by Strydom (2011:126).

A copy of the mini-dissertation is held at the UP’s Academic Information Centre in a hard copy format as well as at the Laudium Mental Health Society. Additionally, the researcher will write and submit an article for possible publication.

### **3.6.7 Debriefing of participants**

This process involves debriefing sessions after the study, where the researcher can minimise possible harm that was done to the participants and rectify any misperceptions that participants may have had (Strydom, 2011:122).

The researcher conducted debriefing sessions with each participant after the interview. If any further counselling was required, the participants were referred to the Social Workers at the Laudium Mental Health Society.

## **3.7 SECTION 1: EMPIRICAL FINDINGS**

In this section, the research findings will be presented and discussed. Biographical data of participants followed by the discussions of themes and sub-themes are presented. Research findings are substantiated by literature. Twelve participants were interviewed and therefore, twelve participants took part in the study.

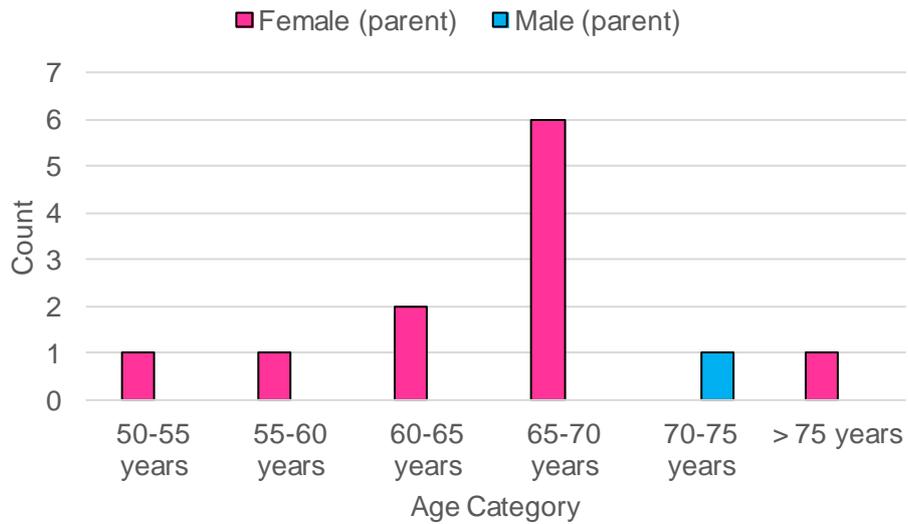
### **3.7.1 Biographical information**

The present study focused on a parent that has an adult child that suffers from an intellectual disability and that accessed services at the Laudium Mental Health Society.

The following biographical information was collected:

- Age of the participants
- Gender of the participants
- Marital Status of the participants
- Highest Educational qualification of participants
- Age of the child
- Gender of the child
- Summary of participants' background information

### 3.7.1.1 Age and gender of the participants



**Figure 1: Age and gender of the participants**

In Figure 1, the age and gender of the participants are shown. There were eleven females and one male participant. The majority of the participants were between 65 and 70 years old. One female participant was older than 75. Two female participants were between 60 and 65 years old. One female participant was between 55 and 60 years old. One female participant was between 50 and 55 years old. One male participant was between 70 and 75 years old. Cuskelly (2006:20) mentions that the majority of primary carers of adults with intellectual disability are mothers, which is evident in Figure 1.

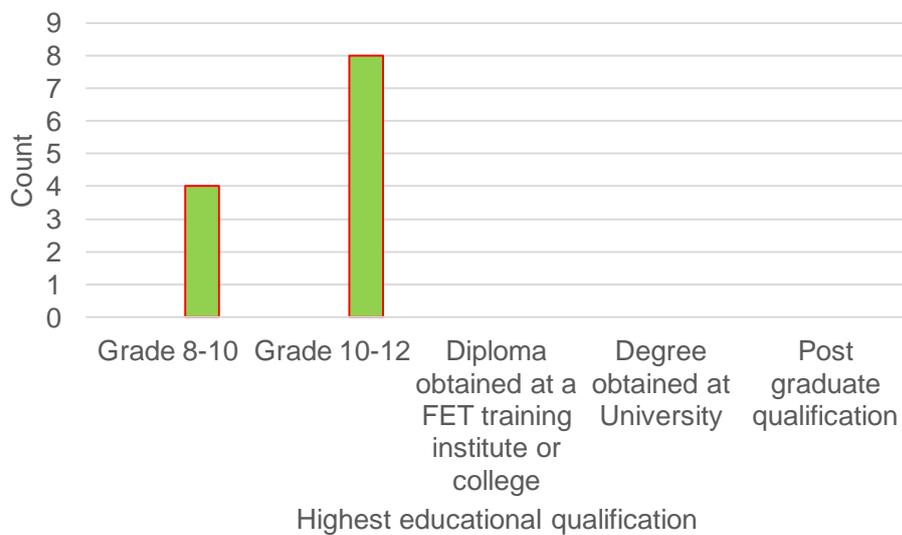
### 3.7.1.2 Marital status of the participants



**Figure 2: Marital status of the participants**

In Figure 2, the marital status of the participants is shown. The majority of the participants are married but three participants are widowed. Namkung, Song, Greenberg, Mailick and Floyd (2015:522) found in their study that there was not an increased risk of divorce associated with having a child with intellectual disability. Their finding is also applicable in the present study because none of the participants were divorced despite experiencing challenges when caring for the adult children with intellectual disabilities.

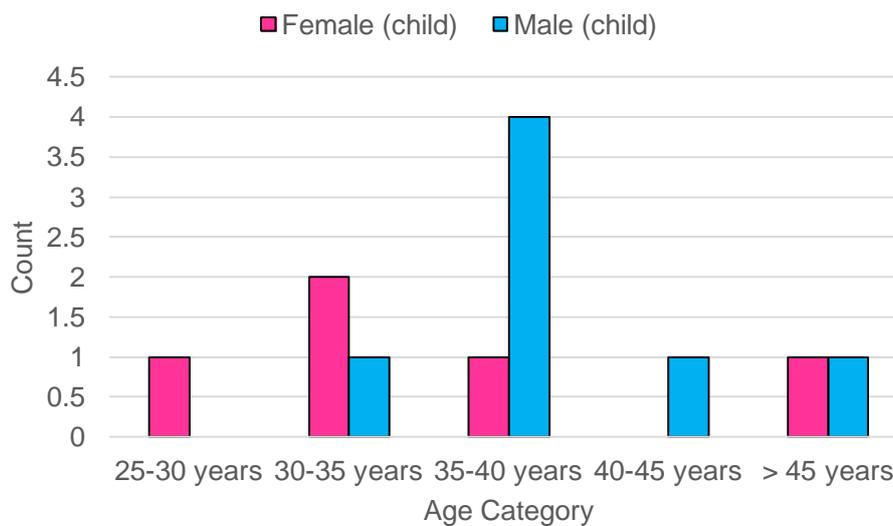
### 3.7.1.3 Highest educational qualification of participants



**Figure 3: Highest educational qualification of participants**

In Figure 3, the highest educational qualification of participants is shown. Four of the participants have a Grade 8 to Grade 10 as their highest level of education; while eight of the participants have a Grade 10 to Grade 12 as their highest level of education. None of the participants have obtained any tertiary qualifications.

### 3.7.1.4 Age and gender of the child



**Figure 4: Age and gender of the child**

In Figure 4, the age and gender of the participant's adult child is shown. There are five female children and seven male children. One male child is between 30 and 35 years old. Four male children are between 35 and 40 years old. One male child is between 40 and 45 years old. One male child is older than 45 years old. One female child is between 25 and 30 years old. Two female children are between 30 and 35 years old. One female child is between 35 and 40 years old. One female child is older than 45 years old. Nichol and Adnams (2016:533) report that male predominance of all intellectual disabilities is at a 3:2 ratio, which is also evident in the present study.

### 3.7.1.5 Summary of participants' background information

In the following section, the researcher provides detailed background information regarding the participants as well as mentioning any history of disability in the family of origin.

*Participant 1* is a 69 year old female. She is a pensioner, widowed and her highest level of education is Grade 12. She attended a university but did not complete her BCom degree. She had two children but the youngest son died. Her oldest and now only son is 46 years old and has an intellectual disability. There is no history of disability in the family of origin.

*Participant 2* is a 66 year old female. She is a pensioner, married and her highest level of education is Grade 8. She has four children. Her third oldest daughter is 38 years old and has an intellectual disability. There is a history of disability in the family of origin. Her maternal niece has a physical disability.

*Participant 3* is a 61 year old female. She is a pensioner, married and her highest level of education is Grade 12. She is currently furthering her Islamic studies. She has four children. Her youngest daughter is 31 years old and has an intellectual disability. There is no history of disability in the family of origin.

*Participant 4* is a 70 year old male. He is a pensioner, widowed and his highest level of education is Grade 9. He has four children. His youngest son is 35 years old and has an intellectual disability. There is no history of disability in the family of origin.

*Participant 5* is a 79 year old female. She is a pensioner, widowed and her highest level of education is Grade 8. She has seven children. Her youngest son is 44 years old and has an intellectual disability. There is no history of disability in the family of origin.

*Participant 6* is a 65 year old female. She is a pensioner, married and her highest level of education is Grade 12. She has four children. Her oldest son is 38 years old and has an intellectual disability. There is a history of disability in the family of origin. Her husband's niece has been diagnosed with autism.

*Participant 7* is a 65 year old female. She is a pensioner, married and her highest level of education is Grade 10. She has four children. Her third oldest son is 39 years old and has an intellectual disability. There is a history of disability in the family of origin. Her brother-in-law's granddaughter is diagnosed with cerebral palsy.

*Participant 8* is a 54 year old female. She is a housewife and a Body Talk practitioner, married and her highest level of education is Grade 12. She attended a university but did not complete her BA degree. She is still pursuing her studies in energy healing. She has three children. Her oldest daughter is 33 years old and has an intellectual disability. There is no history of disability in the family of origin.

*Participant 9* is a 66 year old female. She is a pensioner, married and her highest level of education is Grade 12. She has three children. Her oldest daughter is 45

years old and has an intellectual disability. There is a history of disability in the family of origin. Her middle daughter and her husband's niece are diagnosed with Bipolar Disorder and her youngest daughter has learning difficulties.

*Participant 10* is a 56 year old female. She is a housewife, married and her highest level of education is Grade 8. She has four children. Her third oldest daughter is 27 years old and has an intellectual disability. There is no history of disability in the family of origin.

*Participant 11* is a 60 year old female. She is a pensioner, married and her highest level of education is Grade 10. She has four children. Her second oldest twin sons is 33 years old and they both have an intellectual disability. There is a history of disability in the family of origin. Her brother-in-law has a physical disability and her niece has an intellectual disability.

*Participant 12* is a 65 year old female. She is a pensioner, married and her highest level of education is Grade 10. She has two children. Her youngest son is 35 years old and has an intellectual disability. There is no history of disability in the family of origin.

### 3.8 SECTION 2: THEMATIC ANALYSIS OF THE STUDY

There were various themes and sub-themes that were generated from the acquired data during the data analysis. Each theme is subsequently discussed using verbatim quotes from the interviews to support the themes and literature is applied to substantiate the findings.

The themes and sub-themes are thematically summarized in Table 6:

**Table 6: Summary of themes and sub-themes for the thematic analysis**

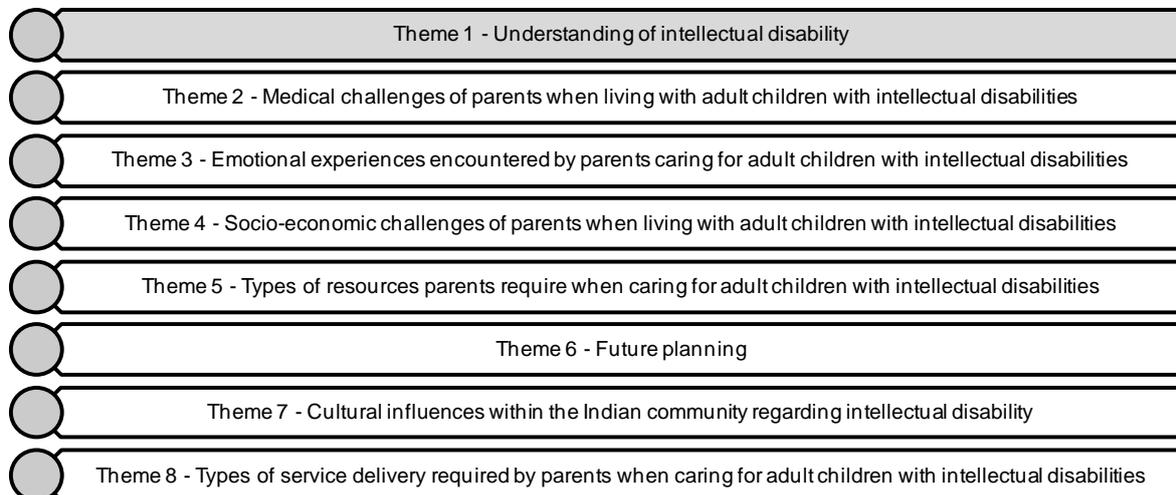
THEMES	SUB-THEMES
<b>Theme 1</b> Understanding of intellectual disability	1.1 Insight into the child's intellectual disability 1.2 Cause of the intellectual disability 1.3 Limited life span prognosis
<b>Theme 2</b> Medical challenges of parents when living with	2.1 Associated health conditions, co-morbidities and psychiatric disorders

THEMES	SUB-THEMES
adult children with intellectual disabilities	2.2 Medication 2.3 Therapy
<b>Theme 3</b> Emotional experiences encountered by parents caring for adult children with intellectual disabilities	3.1 Despair 3.2 Acceptance 3.3 Hope 3.4 Hurt
<b>Theme 4</b> Socio-economic challenges of parents when living with adult children with intellectual disabilities	4.1 Employment 4.2 Impact of social and community life on the family and the child 4.3 Support systems 4.3.1 Immediate family 4.3.2 Extended family 4.3.3 Domestic worker 4.3.4 Neighbours 4.3.5 Friends 4.3.6 Religious organisations 4.4 Family life/relationships 4.4.1 Influence on marital relationships 4.4.2 Influence on sibling relationships 4.5 Type of care required 4.6 Finances 4.7 Community reactions
<b>Theme 5</b> Types of resources parents require when caring for adult children with intellectual disabilities	5.1 Lack of special schools in the community
<b>Theme 6</b> Future planning	
<b>Theme 7</b> Cultural influences within the Indian community regarding intellectual disabilities	7.1 Role of culture on perceived belief system
<b>Theme 8</b> Types of service delivery required by parents when caring for adult children with intellectual disabilities	8.1 Required services for better care 8.2 The role of professional services

The researcher utilised the biopsychosocial model as her theoretical framework for the present study. In order to ensure that all the needs of an individual are met for a comprehensive intervention, a biopsychosocial approach is used for assessment and

management in mental health care (Thom, 2015:80). In this present study, there are 8 themes, which is shown in Table 6.

### 3.8.1 Theme 1 - Understanding of intellectual disability



From the participants' responses with regards to understanding intellectual disability, the researcher identified three aspects that highlight the participants' understanding of intellectual disability. These three aspects relate to their insight into their child's intellectual disability, the causes of intellectual disabilities and the prognosis for their child with intellectual disabilities.

#### 3.8.1.1 Sub-theme 1.1 - Insight into the child's intellectual disability

The majority of the participants did not receive a formal diagnosis but they all displayed fair insight regarding the understanding of their children's intellectual disability. The following quotes provide examples of the participants' insight/understanding into their children's intellectual disability:

*Participant 3: "Look, her understating is not normal, not like normal children, I mean you know, she is now 31 years old. Her understanding intellectually will be maybe 6 to 8 years, I think...I think she can do things to a certain degree."*

*Participant 9: "I know she is not going to be as normal as all children. She is going to need help, her future has got to be planned...But she is not going to be self-sufficient..."*

*Participant 11: "No, they say it is like no they are like mentally disabled, so that's how we find out." [Researcher: Did they explain to you what it*

*meant?] “No...you know like because like now, they are now small children so you have to got to do things for them like how you do it for small child.”*

*Participant 12: “Look his age is 35; he thinks he is like 7 to 8 years... He can do everything, he needs supervision.”*

Prior to the DSM 5, the degree of severity of the intellectual disability was based primarily on IQ levels and not on assessing their functioning in the three domains such as the conceptual, social and practical domains (APA, 2013:809). In Western society, 40 to 60% of parents with children with intellectual disability receive a precise diagnosis (Boström, Broberg & Hwang, 2009:1). In the present study, insight into the child’s intellectual disability contributes to the understanding of the biological factor in the biopsychosocial model.

### **3.8.1.2 Sub-theme 1.2 – Cause of the intellectual disability**

One cause of intellectual disability reported by some of the participants was prematurity (premature birth), as shown by the following quotes:

*Participant 2: “When she was born, she was seven and a half [months old].”*

*Participant 10: “Then the time when she was born she was a premature baby, 8 months.”*

The peri-natal causes of intellectual disability include prematurity, birth injuries, birth asphyxia and neonatal disorders such as septicemia and placental insufficiency (Einfeld & Emerson, 2008:824; Nichol & Adnams, 2016:533). In the present study, premature birth is considered to be one of the biological factors in the biopsychosocial model.

### **3.8.1.3 Sub-theme 1.3 – Limited life span prognosis**

Four of the participants were given a poor prognosis regarding their children’s intellectual disability. The following quotes are examples of the limited life span prognosis they were given for their children:

*Participant 4: “...they gave me a time that his lifespan will only be to 14 years that is all that they told me and now he is 35.”*

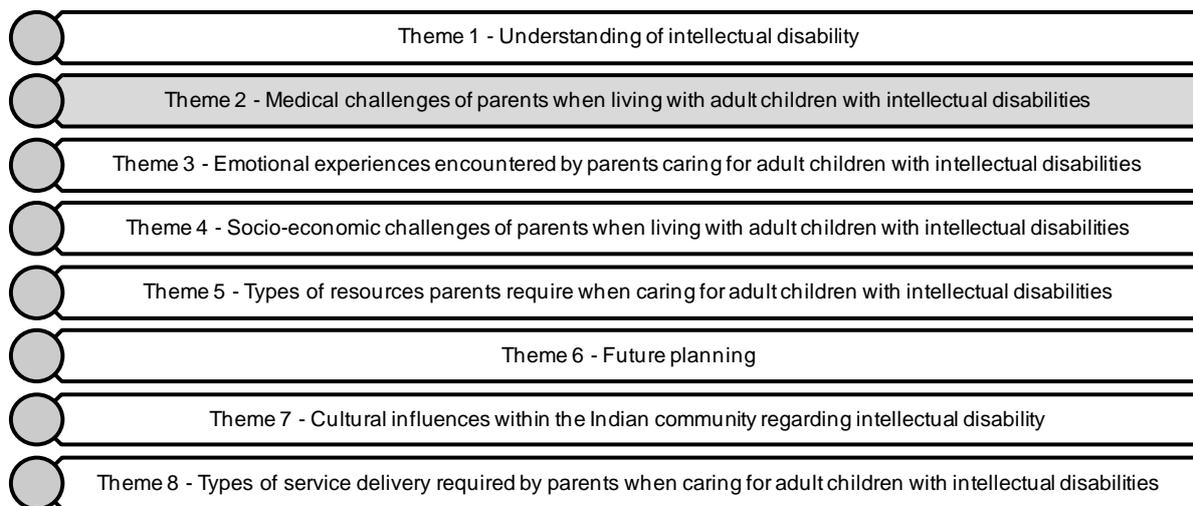
*Participant 5: “No they just told me he would live until 18 but he passed that...”*

*Participant 8: “And then you see one of the prognosis [was that] these children don’t live long, they [live] up to 21. So now she is already 33...”*

*Participant 10: “...only live at the age of 6...”*

In the US, the life expectancy of people with intellectual disability is close to the life expectancy of the general population as a result of improvements in medicine, technology and education (Woodman, Mailick, Anderson & Esbensen, 2014:496). The lack of education, technology and medicine associated with intellectual disability could have led to the poor prognosis of the children in the present study. Physical health and lifespan are considered to be the biological factors that contribute to the biopsychosocial model (Corcoran & Walsh, 2013:14).

### **3.8.2 Theme 2 – Medical challenges of parents when living with adult children with intellectual disabilities**



The researcher could identify three aspects from the participants’ responses with regards to the medical challenges of parents when living with adult children with intellectual disabilities. These medical challenges included associated health conditions, co-morbidities and psychiatric disorders, medication that is received and therapy that is needed.

### 3.8.2.1 Sub-theme 2.1- Associated health conditions, co-morbidities and psychiatric disorders

One participant did not report any health conditions, co-morbidities or psychiatric disorders in the child. Seven participants reported that their children suffer from a health condition; namely, epilepsy. Two participants reported that their children suffer from other health conditions: one child suffered from diabetes mellitus and hypertension while the other suffered from diabetes mellitus and high cholesterol levels. Four of the participants reported that their children have a physical disability and use a wheelchair. Three participants whose children displayed psychiatric symptoms could not provide a psychiatric diagnosis. Two participants reported that their children suffer from health conditions and psychiatric symptoms, while another two participants reported that their children suffer from health conditions, co-morbid conditions as well as psychiatric symptoms. The following quotes are examples of the associated health conditions, co-morbidities and psychiatric disorders:

*Participant 1: "Well, he has to have treatment, he is epileptic."*

*Participant 4: "He is only on medication for epilepsy...then his blood pressure tablets and diabetic...From personal observation, the adult child has a physical disability."*

*Participant 5: "When I took him, he was 3 months old, they tested him, blood test and then the doctor said he is Down Syndrome... my child was acting very funny he don't sleep late night and he is laughing and making noise (psychiatric symptoms)...but he gets gout."*

*Participant 7: "... can be irritable bowel syndrome or it can be other things. Or it can through his epilepsy, through that tuberous sclerosis, his kidneys might be also..."*

*Participant 12: "At the moment, if you want to know he is taking, he is diabetic, he has got an under active thyroid.... cholesterol..."*

There is an increased risk of a number of congenital physical malformations and neurodevelopmental disabilities in people with intellectual disability (Nichol & Adnams, 2016:537). They may develop chronic primary and secondary medical problems that occur more commonly than in the general population. Certain genetic syndromes may also have clinical features or health conditions as part of the phenotype (Nichol & Adnams, 2016:537). The entire spectrum of psychiatric disorders described in the general population manifest in people with an intellectual

disability but they are also more susceptible than people with normal intelligence to developing co-morbid psychiatric conditions (Nichol & Adnams, 2016:540).

In the present study, the most common chronic health condition associated with intellectual disability was epilepsy. Thompson et al. (2014:856) report that there is an “increased prevalence of epilepsy among those with intellectual disability when compared with the general population.” Epilepsy carries a significant burden for families caring for an adult child with an intellectual disability because it is typically severe in presentation, it is the most frequently reported co-morbidity, refractory to treatment and “it is incrementally more prevalent and complex among those who have more severe levels of intellectual disability” (Thompson et al., 2014:856). In the present study, one participant has a child who is also diagnosed with Down Syndrome. It is the most common genetic cause of intellectual disability, occurring in approximately 1 in 800 live births and the risk of Down syndrome increases with maternal age (Einfeld & Emerson, 2008:824). Having health conditions, co-morbidities and psychiatric disorders affects a person’s physical health and therefore these conditions are contributors to the biological factor in the biopsychosocial model (Corcoran & Walsh, 2013:14).

### **3.8.2.2 Sub-theme 2.2 – Medication**

Seven participants received medication for a health condition and/or for psychiatric symptoms. Six participants reported that their children were receiving either Epilim or Tegretol or both Epilim and Tegretol for their epilepsy. Three participants reported that their children were receiving Largactil and/or Risperdal which is common psychiatric medication for psychotic disorders such as Schizophrenia.

*Participant 1: “Tegretol...”*

*Participant 4: “Epilim 200 and then his blood pressure tablets (unsure of name) and ... glucovance.”*

*Participant 5: [She showed the researcher the medication], which was Epitec, Largactil and Orphenadrine.*

*Participant 8: “She has Epilim and Tegretol.”*

*Participant 9: “...they had her on Largactil and Epilim and what else? Tegretol...put her on to just 1mg of Risperdal at night.”*

*Participant 12: "...when he was little he used to take Ritalin, but a short while also...he is taking Glucovance 500 twice daily...I give him Esperol 20... Hydroxin..."*

Bentley and Molteno (2015:610) mention that people with intellectual disabilities should be treated with the same medications used in the general population once a mental illness has been diagnosed but certain precautions should be noted. People with intellectual disabilities are more sensitive to medication and its side-effects. They may exhibit paradoxical reactions to certain medications more frequently than the general population (Bentley & Molteno, 2015:610). Einfeld and Emerson (2008:830) report that people with intellectual disability often receive prescriptions that have not been indicated by a diagnosis. Alternatives to medications are rarely explored and evaluations of effects and side effects were exceptions.

Due to pressure or being presented with a crisis situation, mental health professionals are frequently prescribing medication to control disturbed behaviour. However, medication is most beneficial when it follows a comprehensive assessment of the individual's emotional and behavioural disturbance, allowing the formulation of precipitating and ameliorating factors and an assessment of the efficacy of all the past modes of treatment (Einfeld & Emerson, 2008:830). In the present study, some of the participants' children were receiving psychiatric medication without being diagnosed with a psychiatric disorder.

The use of medication affects a person's physical health and is therefore considered to be a biological factor in the biopsychosocial model (Corcoran & Walsh, 2013:14).

### **3.8.2.3 Sub-theme 2.3- Therapy**

All the participants reported that their children were receiving some form of therapy such as speech therapy, occupational therapy and/or physiotherapy when they were attending a special school. Currently, only two participants reported that their children were actively receiving physiotherapy for their physical disability. Two participants reported that their children received alternative treatment; namely, Chinese treatment for the physical disability and Body Talk/Body Healing for the intellectual disability and associated health conditions. The following quotes provide examples of the therapy that participants' children have received throughout their life cycle:

*Participant 6: "But I use to have a speech therapist that use to come home as well but then afterwards when he started going to school then they had an occupational therapist, speech therapist, music therapist and all that."*

*Participant 7: "...that is how we met her and through her we got physio and occupational therapy, volunteers, white ladies that came to help us and through that we got him crawling and walking."*

*Participant 8: "...and then I took my child there [body talk therapy] and I found amazing results. You know like firstly how things just begin to normalise, her skin condition improved, and then her sense of smell..."*

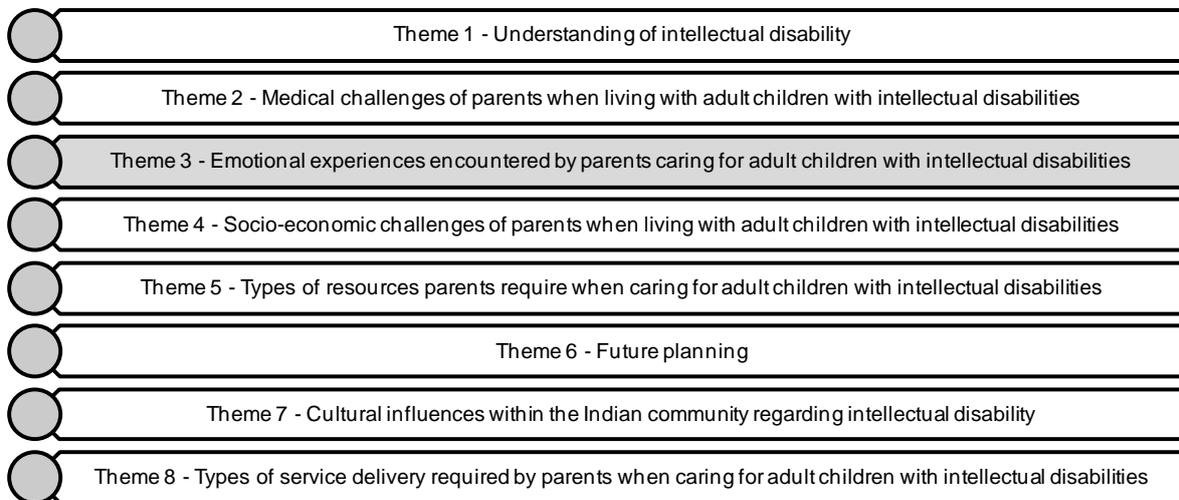
*Participant 9: "But the damage was already done; the specialists say that this child is going to be a disabled child. They didn't, he didn't know what disability because she start, we started excessive speech therapy, occupational therapy..."*

*Participant 11: "...I think it was a specialist, a neurosurgeon and then I asked him like can I take them for physio, so he said you can try. Then I took him to the Chinese people, I took him about 10 to 12 times there, then I see like nothing happen, and I left it there because it is costly."*

The unique contributions of occupational therapy to people with intellectual disabilities are in its ability to provide professional solutions to the functional limitations such as activities of daily living, learning, work, play, leisure and social participation they experience throughout their life cycle (Yalom-Chamovitz, Selanikyo, Artzi, Prigal & Fishman, 2010:4). Therefore, it is important that adult children with intellectual disabilities receive therapy throughout their life cycle and not only in their schooling years as mentioned by the participants.

In the present study, the biological factors addressed the insight into the child's intellectual disability, cause of the intellectual disability, limited life span prognosis, associated health conditions, co-morbidities and psychiatric disorders, medication and therapy. The biological factors reflect the genetic, biochemical and physical factors that both influence a patient's problem and lead to helpful medical interventions (Kaplan & Coogan, [sa]:19).

### 3.8.3 Theme 3 – Emotional experiences encountered by parents caring for adult children with intellectual disabilities



From the participants' responses, with regard to the emotional experiences encountered by parents caring for adult children with intellectual disabilities, the researcher identified various positive and negative emotions that they experienced as a result of caring for their child with an intellectual disability. Despite participants experiencing stress, hurt, depression, their children were also a source of self-growth, nurturing and strength.

#### 3.8.3.1 Sub-theme 3.1 – Despair

All the participants reported some form of despair at some stage during providing care for their children with an intellectual disability. The following quotes provide examples of despair when caring for adult children with intellectual disabilities:

*Participant 1: "It's draining me, it's draining me. [Participant says the researcher's name], it is draining me now. Because it is, you know I have no freedom I have, every single day I have got to tell him how to bath and he knows how to do it, he knows but I have got to say your arms I have got to say the next thing."*

*Participant 3: "It can sometimes be very draining. Generally, I plan myself around the whole situation so it's not so bad, but it can be sometimes very draining. It just, I can't just say, you know what I am just going somewhere today and forget about it, I have to consider taking her or having her cared or whatever the case may be."*

*Participant 4: "I just feel like crying. Because you are all by yourself, there is things that you want to do for him which he can't do, and thing is I went for a triple bypass, it makes it even worse and we are too old by ourselves. Then you have to prepare meals for him and myself, it is very difficult."*

*Participant 6: "He, my child was never interested so it was very very difficult to keep him entertained or to look after him....I was so tired physically and mentally..."*

A study by Chadwick, Mannan, Iriarte, McConkey, O'Brien, Finlay, Lawlor and Harrington (2012:124) mentions that parents experience negative aspects of life as a result of caring for adult children with intellectual disabilities such as feeling exhausted, alone, isolated and overwhelmed. These feelings can be considered synonyms of despair. Corcoran and Walsh (2013:15) mention that "when caregivers are unable to regulate their children's and their own emotional states, the children do not have opportunities to develop effective strategies for responding to their own emotions or those of others." Therefore emotions refer to the psychological factors in the biopsychosocial model.

### **3.8.3.2 Sub-theme 3.2 – Acceptance**

The majority of the participants reported having found acceptance with their children with intellectual disabilities and the challenges associated with the condition. The following quotes provide examples of acceptance when caring for adult children with intellectual disabilities:

*Participant 2: "I mean it was accepting, accepting her for what she is and all that...I actually, I am very happy; she is, I would say, she is a blessing in my life...I said she is just not a mentally child to me she is just a late bloomer a flower that just blooms late, I said. And this is how I accepted her and this is how society, what you call it, degraded me and all that, but I am proud of her today and I am proud to talk about her. I said there is nothing to be ashamed of."*

*Participant 3: "But fortunately myself, my husband and generally my whole family, we have very strong faith and have accepted it. In fact, now I think it is a very special blessing, it is a special blessing from God you know because not everyone can get a child like that."*

*Participant 8: "When my child was born and I was given a prognosis of her and I felt oh my, this is what I wanted, you know like God gave it to me, but in a different way, in a way that He wanted it at a time when He saw*

*that it was right...when I found out that she was mentally retarded, I just accept it, I knew this is what I wanted..."*

*Participant 9: "Terribly spoiled and that and we accepted her for slow learning. We knew she is going to school but she is not going to cope but nevertheless we put her into school..."*

A study by Chadwick et al. (2012:123) mentions that parents gained joy, pride and inspiration as a result of having an adult child with an intellectual disability. Therefore, these feelings can be considered synonyms of acceptance. Corcoran and Walsh (2013:15) mention that "the nature of one's coping strategies is also a general risk or protective mechanism." Therefore coping strategies such as acceptance refer to the psychological factors in the biopsychosocial model.

### **3.8.3.3 Sub-theme 3.3 – Hope**

The majority of the participants reported that they were hopeful about the future despite having children with intellectual disabilities. The following quotes provide examples of hope when caring for adult children with intellectual disabilities:

*Participant 2: "Yes and as years went by I did realise it, she has brought a lot of spirituality and calmness into my life. You know the stableness in my life, to be patient with her and to tolerate her challenges...yes. I mean look I could have carried her till eight or what and she could have been stillborn, it was meant for her to be born. I realise that it was meant for her to be with me. It is maybe my past life and her place that we are together in this life. I have accepted her for what she is. I don't mind because like I said you know what I am very proud of her I am not ashamed of her, she like the angel in my life. She is definitely they come and God gives us these challenges so."*

*Participant 3: "I think so, you become more accepting, you become more content. I think you look at life at a different level. When you are younger it is different as you get older. I think your outlook changes totally as you get older."*

*Participant 8: "...okay that is the one thing I do and I always advise other parents nurture yourself first, that also I heard from one of the them about this, if you are not happy with yourself, she is going to pick up all your vibes, right, so if I am hungry and I am eating with the family, I will rather enjoy myself with them, we laugh, we talk we eat when I am done I will dish up for her and then I will leave to feed her ..."*

*Participant 10: "Hmm as long as you are positive everything will fall into place, but if you are going to harp on things and go on and tell yourself, how many people can you complain to, is going to listen to you? So turn it*

*the other way around and say you know I have got it I have got to move on, I have got to make plan B now, so that is why I say, I am a mother, a doctor [motherly role of being a doctor]...”*

A study by Chadwick et al. (2012:123) mentions that parents expressed optimism about their lives and the life of the adult children with intellectual disabilities. This feeling is considered a synonym of hope. Corcoran and Walsh (2013:15) mention that “the nature of one’s coping strategies is also a general risk or protective mechanism.” Therefore, coping strategies such as hope refer to the psychological factors in the biopsychosocial model.

#### **3.8.3.4 Sub-theme 3.4 –Hurt**

Some of the participants reported experiencing hurt from family members and community members as a result of having children with intellectual disabilities. The following quotes provide examples of hurt when caring for adult children with intellectual disabilities:

*Participant 1: “Oh yes you know, it is heart breaking because you see other kids his age who are married now, who have children I mean at this point in time in my life if my child was normal, I would have grandchildren, I would have had a family. Right now I don’t have anybody, it is just him and I...”*

*Participant 4: “Exactly. It is like when they look at him, like they haven’t seen anybody like him. You as a parent will feel the pain so I said no I would rather have him at home. They won’t treat him, in front of you everything will be fine.”*

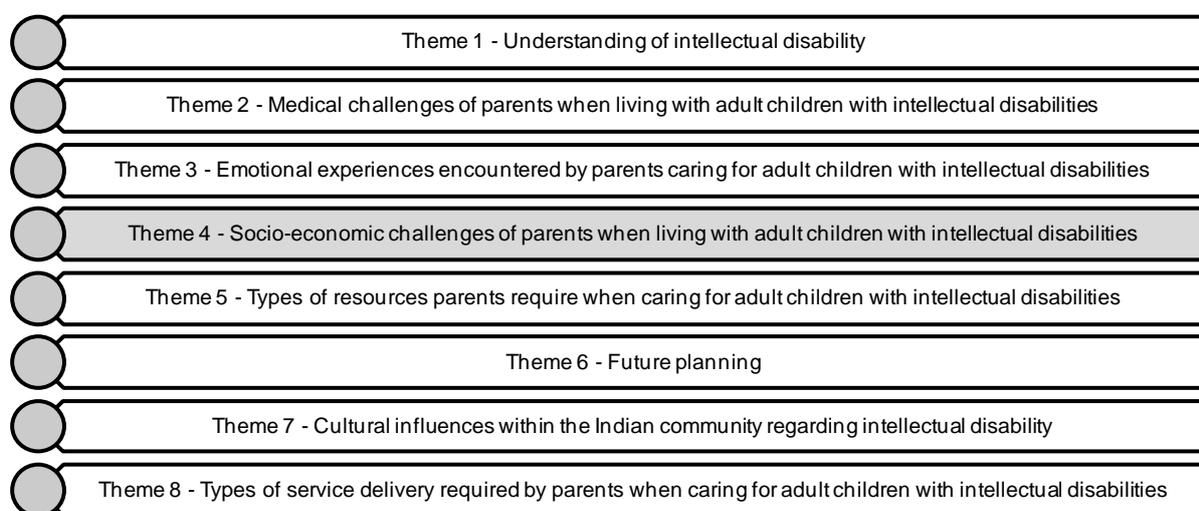
*Participant 6: “you know lots of abuse, I think it is abuse, you know. Because you’ve got to deal with this child and they abuse you by telling you what kind of a mother you are. That you don’t even know your own child or things like that. No, I felt very hurt, that time, I mean when you’re young you have this, you can’t cope.”*

*Participant 7: “It is tiring, you cannot have a conversation, and some people are uncomfortable, so now you are going to worry of that person and my child, so it is a lot of stress. So we just decided, people can say what they want to, we are better off at home.”*

Care-giving for adults with intellectual disability can have a substantial impact on the well-being of the parents (Esbensen, 2011:143) as is evident with the above quotations.

The psychological factors allow the professional to assess and select interventions for developmental and psychological issues that has altered the normal development of both self-efficacy and self-esteem (Kaplan & Coogan, [sa]:19). In the present study, the psychological factors addressed the emotional experiences encountered by parents caring for an adult child with an intellectual disability; namely, despair, hope, hurt and acceptance.

### **3.8.4 Theme 4 – Socio-economic challenges of parents when living with adult children with intellectual disabilities**



From the participants' responses about socio-economic challenges, the researcher identified seven aspects that highlight the participants' and their adult children's challenges when living with intellectual disabilities. These seven aspects include employment challenges, the impact of social and community life on the family and child, the types of support systems, the influence on the family and child with regards to marital and sibling relationships, the type of care required when caring for adult children with intellectual disabilities, finances and community reactions.

#### **3.8.4.1 Sub-theme 4.1 – Employment**

Four participants reported that they were self-employed because they needed additional income to meet their children's needs and chose this type of employment because it offered flexi hours. Two participants reported that they have given up their full-time job and chose self-employment to provide care to their child. Three participants reported that they worked full-time because they had help in the form of

family members and domestic workers. Three participants reported that they never worked because they were either financially supported by their spouse or other children. The following quotes provide examples of the employment challenges parents face:

*Participant 2: "It is now about 15, 18 years [ago that] I started doing catering, thank God for that, that is helping me a lot, with her medication, her well-being, her clothes, whatever her needs are. I am doing that for her."*

*Participant 3: "No, I was always unemployed, I did a little bit of sewing at home but I was at home and I was my own boss so I could do it at my own pace so I could attend to her...so I had to do the sewing to help with the income and all the therapies were really expensive."*

*Participant 4: "No I asked my boss because I was working 19 years for him, I told him I resign or otherwise you give me a job from 7 to 5, and he asked me why, and then I explained, I have got a child like this, and then that is the time they gave me. I worked only for more 3 years and then you know what I am going to stay at home. Not stay at home, do some other work, but I'll be daily at home."*

*Participant 8: "...they needed extra help (tutoring Maths, English and Afrikaans) the parents use to bring them over, so that was my sort of income...I would have wanted to go and work in a hospital or school and I did not want to go away fulltime because I wanted to be part of her."*

*Participant 11: "Yes, you know I was telling you I made pie dough." [Researcher asks: Is that your second income] "Yes, I do it like at home so it is like now; it is not so busy but as long as I can manage to that little, it is fine."*

Spencer (2014:24) states that having children with intellectual disabilities increases the "likelihood of mothers reducing working hours or stopping work all together." Song et al. (2014:131) report evidence in their study that shows the physical health of parents of adult children with intellectual disabilities is more vulnerable to the adverse influence of the lack of a flexible work schedule and to the spill-over of stress from work to family life than parents of adult children without disabilities. Social factors refer to family relationships, socio-economic status and social support (Hatala, 2012:51). Therefore, in the present study, employment is considered to be a social factor in the biopsychosocial model.

### 3.8.4.2 Sub-theme 4.2 – Impact of social and community life on the family and child

All the participants reported a lack of a social and community life, which influences the family as well as the individual with the intellectual disability. Eight participants reported difficulties in their social and community life because of behavioural problems, lack of facilities available for their children's physical disability as well as stigma within the community. The following quotes are examples of the influence that social and community life has had on the family:

*Participant 1: "...he [my child] doesn't allow me to interact with anybody, doesn't want me to. If anybody comes home he will always interrupt my conversation and if I have visitors who would stay a while, or maybe have a meal or tea or whatever, he will say well it is time for you to go. And it is a big joke now, but it irritates me hey, because I need their company. I need them as much as they came to visit me, I need them because I am alone. And then also when I go, if I had to come and visit you [the researcher] for instance, he will let me sit 5, 10 minutes and then he'll start, let's go, let's go, and it will go on and it will go on to a point where I cannot even talk to you [the researcher]."*

*Participant 7: "I can't go nowhere, there is no shopping, nothing...The only thing is no social life...I say hell the thing is that my child walks but the thing is I can't go anywhere with him. In fact we'll go to a mall we would be so tired just watching him move around restless, you can't concentrate you cannot do anything."*

*Participant 8: "No, because those are more formal activities and when she starts screaming then it becomes a problem..."*

*Participant 10: "Look she has got her things where she likes to tear paper and she likes, sometimes she just randomly scream and if you take her to a movie for example she would just randomly scream and people get annoyed...So in that way we have to leave out a lot of socialising, a lot of gatherings and things the others just do."*

Bentley and Molteno (2015:605) mention that the adult child's behaviour or even just their different appearance may limit the parent's social life. Corcoran and Walsh (2013:16) mention that there are several patterns in family functioning that are "...indicative of families in which mental disorders develop, among them hostility, conflict, isolation, low cohesion, enmeshment and an absence of nurturing." Family functioning includes the influence the intellectual disability has on the family's social and community life and is therefore considered to be a social factor in the biopsychosocial model.

All participants reported that their children did not partake in social activities nor did they develop friendship groups with their peers. They preferred to be alone or if they did socialise it was with younger children such as the participants' grandchildren or other family members. Some participants reported that their children were emotionally dependent on their parents and therefore would not want to go out without them; while other participants reported a lack of facilities for people with intellectual disabilities or physical disability. The following are examples of quotes on the influence that social and community life has had on the child with intellectual disabilities:

*Participant 1: "...I try anyway, to take him to a family where there are children, he obviously communicates better with younger children and likes to talk to them and ask them who they are and what they're doing..."*

*Participant 2: "No, like I said she doesn't have friends and she doesn't go out with friends or will not go out...Yes, she will keep to herself. She will definitely, until she knows you and until you will talk to her, when she finds comfort in you, she will talk to, that is how she is."*

*Participant 3: "No, she doesn't go out on her own, she can't socialise. It is everywhere where we go, we take her with. She won't be able to mix with friends and make a conversation, she doesn't do that. Now I have got a grandson she gets along with him and my granddaughters, she gets along with them, she would talk to them but generally she doesn't just make conversations."*

*Participant 6: "...but now even we don't take him out much now because he doesn't like it." [Researcher asked: does he have friends of his age group?] "No has got nobody. In fact, if he is outside he is aloof and if we'll be down for example then he will go up and if we'll go up then he will come down, he doesn't want to, unless he wants to socialise or mix with you or sit with you, but if you go and he doesn't want to, he will run away."*

*Participant 7: "My child before he was active, he will walk around, I mustn't forget the gate open, he is out. But these past few years he is extremely quiet. Like I tell you this is his environment he is safe here, take him out, it is finished he will not sit still, he knows he is not at home. He is such a restless, walk out of the door to try and get in the car to come away home. I can't even visit my daughter with him."*

*Participant 8: "Yes, I have noticed with her as well she is more comfortable at home...but socially I would say now she prefers being on her own. Because when I had my other daughter's engagement and I had a lot of people here and I brought her here for a while she was ok you know she was happy and eventually she just, like I understood she just wants to be on her own so I took her back to her room."*

Adult children with an intellectual disability are significantly less likely to move out of their family home, have friends, be employed, have long-term intimate relationships and participate in the life of their communities when compared to their non-disabled peers (Einfeld & Emerson, 2008:823). Corcoran and Walsh (2013:16) mention that there are several patterns in family functioning that are "...indicative of families in which mental disorders develop, among them hostility, conflict, isolation, low cohesion, enmeshment and an absence of nurturing." Family functioning includes the influence that the intellectual disability has on the adult children's social and community life and therefore forms part of the social factors in the biopsychosocial model.

### **3.8.4.3 Sub-theme 4.3 – Support systems**

All the participants reported six types of support systems namely; immediate family, extended family, neighbours, friends, domestic workers and religious organisations.

#### **3.8.4.3.1 Sub-theme 4.3.1 – Immediate family**

The participants' immediate family included their spouses and children and the majority of the participants reported that they were extremely supportive in providing care to their child. The following quotes are examples of the support from the immediate family:

*Participant 2: "Yes, it has always been there. If I have to go out with my son, my husband is there and my son is also very protective over her, he would not let anybody verbally abuse her or you know, say we are going to a function and they will tell her what to do or tell her sit here, he will interrupt and say no, let her sit where she wants to, don't tell her what to do, she is quite clever and my son is very protective over her."*

*Participant 3: "No, I can rely on my husband - he is a great support, my husband is really a great support because I wouldn't think of going anywhere with her without him, I need him to be there."*

*Participant 5: "... my one son he lives in [place], Friday he sends driver my child goes to him and his children and they all play football everything then Monday morning they drop him back. And then anytime I must just phone them my child and they are here for me."*

*Participant 8: "I will feed her here on the sofa, once she has her supper then he [husband] takes her to the room, he brushes her teeth and he*

*puts on her pyjamas and puts her into bed for me...Ja, and when we go out to the mall and that, he takes her to the car. You know we have got steps and it is a bit difficult, and he puts her in the car and take the wheelchair and he does that."*

*Participant 9: "The youngest does everything for me, for my child [the child with the intellectual disability] and for the granddaughter. The youngest one does a lot."*

Corcoran and Walsh (2013:16) mention that social support is widely viewed as a multidimensional concept and is commonly defined as the availability of a network of people on whom a person can rely in times of need." Therefore social support includes support from immediate family and forms part of the social factors in the biopsychosocial model.

#### **3.8.4.3.2 Sub-theme 4.3.2 - Extended family**

The majority of the participants reported that their extended family, such as in-laws and siblings, provided very limited support. If they were supportive, their support mostly consisted of emotional support. The following quotes are examples of the lack of support provided by the extended family:

*Participant 1: "Which member of my family, who are all Indians, ever came and took my child for a walk, ever said to me, you have rest today, leave him with us. Today, he will not go to anybody because he has never been." Okay, [parent's name] don't worry today, just leave him with us, we will do whatever it is that we have to do. We will see to him, we will take him out; we will take even for a drive whatever. It never happened."*

*Participant 4: "...I can't leave him by anybody and nobody is asking you to leave him, even the family, there is no more family, and they are around...I couldn't go for the funeral, I asked the family members just to keep him for two hours, they couldn't, they couldn't."*

*Participant 5: "No, they are very older and they got this Alzheimer, my two brother-in-law, one brother-in-law got leukaemia, the sister-in-law one she got a stroke...My sister she is younger like me but she's also got Alzheimer she don't know nothing, she don't know even her children also."*

*Participant 6: "Look I am from Joburg, I am originally from Joburg and my in-laws were here, but they were funny they weren't good with me so they're not going to help me with my child I mean they are the ones that used to, I think they use to enjoy the fact that, this is what happens in family, and I think they use to enjoy all that, like me suffering because he was very naughty, he used to scream, he used to run away, he used to do all those sort of things before. I never got help from them; the only help I got was from my mother."*

The availability of a network of people on whom a person can rely in times of need is defined by social support (Corcoran & Walsh, 2013:16).” Therefore social support includes support from extended family and also refers to the social factors in the biopsychosocial model.

#### **3.8.4.3.3 Sub-theme 4.3.3 – Domestic worker**

Some of the participants reported that their domestic worker played a role in providing support to their child. This could be considered as a form of paid help but the domestic worker’s primary purpose is not to provide care for the adult child with an intellectual disability. The following quotes are examples of the support provided by the domestic workers:

*Participant 6: “...I only had one maid you know since he was 6 months old, I’ve still got the same maid...and I told my maid, so she had to see to him at day...”*

*Participant 8: “I had to my helper at homes that help me, up to now for the little, little things but not on a fulltime basis.”*

*Participant 9: “I rather pay my domestic if I need to go, if my child is not here then the domestic is here so. My domestic will look after her.”*

*Participant 10: “...I had a very good domestic also that time she was helping me she worked 9 years with me and that wasn’t difficult then also because they all learned how to handle her, especially when she has fits, each one will know how to handle her.”*

*Participant 12: “...but he needed a bit (of attention), but then I had a helper...Ja, no he could even stay with my helper.”*

As mentioned above by Corcoran and Walsh (2013:16), the support provided by the domestic worker is a form of social support. Therefore, it is a factor contributing to the social factors in the biopsychosocial model.

#### **3.8.4.3.4 Sub-theme 4.3.4 – Neighbours**

Some of the participants reported that their neighbours were supportive. The following quotes are examples of the support participants received from their neighbours:

*Participant 1: "No, but I found that the Afrikaans friends [neighbours] that I made, they were supportive in the fact that they said, [parent's name], you have got to do this, [parent's name] you've got to do that."*

*Participant 4: "The opposite neighbour always asks me if I want to go somewhere and then he is willing to go there. Because the man's the husband's sister was also retarded she died at the age of 52. He stayed a couple of times there during the day...Ja, they said anytime you want to go do something I can, but you can't take advantage of this, because she has got cancer and they removed a breast and all this."*

*Participant 5: "They good [neighbours]. I can ask them also they will do for me."*

*Participant 6: "And I am thinking to myself my neighbours use to help me, I use to live in [place] and there was a coloured lady and her daughters, they use to help me with my daughter and they use to take her out, or she use to go out, those are my friends so they helped me quite a bit with my daughter and all that."*

*Participant 11: "Like they [neighbours] did help, but I did not simply ask, you can't burden other people, but like if it is really necessary...I would not say that they would moan."*

The neighbourhoods/neighbours represent a source of protection because they provide "...informal social control and social cohesion, neighbours involved in local organisations help to sustain the mental health of children who live in neighbourhoods marked by disadvantages (Corcoran and Walsh, 2013:18)." Therefore, neighbourhood falls under the social factors in the biopsychosocial model.

#### **3.8.4.3.5 Sub-theme 4.3.5 – Friends**

Some of the participants reported that their friends provided limited support. The following quotes are examples of the type of support friends provide:

*Participant 3: "No, I think they are okay, they are supportive."*

*Participant 5: "No, I have but I don't [ask]. I had one friend, opposite [place], but now she passed away. She use to be very fond of my child."*

*Participant 7: "I've got friends they help me a lot but they all now moving away from [place], my closest friend moved now a few weeks back she's also gone to [place]."*

Bentley and Molteno (2015:605) state that exhaustion from caring for an adult child with an intellectual disability may interfere with relationships and therefore friends

and family may be unsure of how to help and may worsen feelings of isolation. Therefore, friendship support is a contributing social factor in the biopsychosocial model.

#### **3.8.4.3.6 Sub-theme 4.3.6 – Religious organisations**

The majority of the participants reported that their religious organisations provided very limited support. The following quotes are examples of the lack of support provided by their religious organisations:

*Participant 7: “I think most of them [religious leaders] many of them don’t even know I’ve got my child.”*

*Participant 10: “Not really. We are not really involved with people (in religious organisations)”*

Corcoran and Walsh (2013:18) mention that “a particular type of social network involving church or religious participation has been associated with positive physical and mental health, as well as with buffering the effects of neighbourhood risk.” Unfortunately, the participants in the present study did not benefit from the support provided by the religious organisations. Many of the religious organisations did not actively involve people with intellectual disabilities. Since religious support forms part of the social network, it contributes to the social factors in the biopsychosocial model.

#### **3.8.4.4 Sub-theme 4.4 – Family life/relationships**

Having an adult child with intellectual disability influences family life/relationships in terms of marital and sibling relationships.

##### **3.8.4.4.1 Sub-theme 4.4.1 – Influence on marital relationship**

Some participants reported problems in their marital relationship because they had no privacy and they could not spend time together. They reported that one spouse always had to remain with the child at home during functions because of behavioural problems or lack of facilities available. The following quotes are examples of the influence on the marital relationships:

*Participant 1: "...we could never sit in my lounge in any house and talk to each other...very ja, you know it was terrible [says researcher's name], it was terrible. We never did anything that was romantic or intimate or anything together. When we moved out of [place] and lived in my son's house for a while, for seven months, my child slept with us, on his own bed in the room, it was a huge room and we didn't wanted to do the stairs and you know my child is not good on stairs, so all three of us were in the room, for seven months. My child was with us 24-7, night and day."*

*Participant 3: "Sometimes I just got to cancel going to any function, I think if I have got nobody to look after her, I decide you know what, I tell my husband you go I will stay at home. Or he stays home and I go, whoever's need is urgent, sometimes we do that if there is nobody and sometimes agh no we don't want to impose on anyone else then one of us must just stay at home and the other one goes."*

*Participant 4: "Well that is where [place] I just told you earlier; when there were any functions or things I would send my wife. I told her you carry on and I will look after him."*

*Participant 8: "Ja maybe a little bit, because look there was a time when my husband would also say let's go and I would like to take my child with, so he feels now he need that little bit time alone why I want to take her with, so there was a bit of a challenge, but now I have overcome it, I have realised it now, I have got to leave her behind and him go sometimes, right."*

Seltzer, Floyd, Song, Greenberg and Hong (2011:480) reported that parents of adult children with intellectual disabilities have significant elevations in marital distress and divorce rates in comparison to couples without children with intellectual disabilities. Despite experiencing marital strain in their relationships, none of the participants in the present study are divorced or separated because within the Indian community, especially amongst the older generation, divorce was not an option culturally or religiously regardless of how severe the circumstances were. Social factors refer to family relationships, socio-economic status and social support (Hatala, 2012:51). Family life/relationships (influences on marital and sibling relationships) form part of the social factors in the biopsychosocial model.

#### **3.8.4.4.2 Sub-theme 4.4.2 - Influence on sibling relationship**

Some of the participants reported that their children's siblings had negative emotions towards them as parents as well as towards the sibling with an intellectual disability. This is because the parent gave more attention to the child with the disability or the

siblings had limited social and community life because of the sibling with an intellectual disability. The following quotes are examples of the influence of sibling relationships:

*Participant 6: "...disadvantage it is difficult, sometimes I feel sorry for them [other children without a disability] because they get left out to a certain extent but you, hard luck. Ja, not that we did it deliberately or that, I mean a few things would have been nice; for example, if we could have taken them out more, we could have gone more, out more as a family which they were deprived of. And then like for example my children were young or that we couldn't go out, you know, we watched a lot sports on TV and that, and when they were small I got them interested formula 1 they use to know about formula 1 this-that and use to ask them, so they said the father taught you this? They said no my mother, because I mean we had to have an environment here that they wouldn't feel left out, you understand? So you had to be little creative."*

*Participant 7: "You have conscious and you live it. Like my eldest son had a very difficult time understanding because my parents were around and they helped me look after them at the school. So he felt, I think he only understands now, he had resentment towards me for abandoning him, but I had no option, but now they understand. My youngest daughter also, she was at the stage when I couldn't take them on holiday anymore I had to give that up totally. It was getting more and more difficult going with my child anywhere and you are not happy. So when she came I stopped going anywhere because she came in a new generation that are out going, friends doing things so she rebelled a lot. Because my daughter got married, my son got married, no she is sitting with me here."*

*Participant 10: "You have to try to, you couldn't do anything and you just have to go on. I had my, with my baby that was there, I had to give him away to my sister. The feeding times were worrying me and nobody has seen it at that time, they felt I was so difficult to let go my child, but then understand that if I am going to breastfeed him, what about my child? I didn't give him first love, they only had, I didn't give him. Age gap was a problem because she was 6 with the baby, but she was 6 in age and real terms she was only 2 months, so which baby must I feed and which baby do I sleep. And then the time when I got him and he was growing up he obviously felt that why did my mother give me away? And he was too young to understand it and he was through the thing so he had his own behaviour and I had to deal with that behaviour."*

*Participant 11: "You know what first he [child] was not living with me. When he was a baby he was with me and when he was about, say maybe 2 weeks or more, then you see they used to cry a lot when they were babies, then my mother-in-law would have my child and then she was like looking after him until it is about now 3 years that she passed away that I brought him back."*

Having a brother or sister with intellectual disability brings both challenges and rewards (Mulroy et al., 2008:225). A study by Rossiter and Sharpe (2001) found that there are some negative effects on sibling's psychological development as a result of having a brother or sister with an intellectual disability (Rossetti & Hall, 2015:121). However, Mulroy et al. (2008:227) report that growing up with a sibling with an intellectual disability provides an experience for "character building" that is not available to their peers. Close personal relationships and psychological benefits were also reported by adult siblings of individuals with intellectual disabilities and female siblings displayed higher levels of volunteerism and experiences in helping professions (Rossetti & Hall, 2015:121). In the present study, female siblings provided more support to their sibling with intellectual disability than male siblings. This could be linked to the fact that within the Indian community, females are expected to fulfil the nurturing and caring role. Hatala (2012:51) mentions that social factors refer to family relationships and therefore family life/relationships (influences on sibling relationships) resort under the social factors in the biopsychosocial model.

#### **3.8.4.5 Sub-theme 4.5 – Type of care required**

Participants reported that they required various types of care when caring for their adult children with intellectual disabilities such as physical, emotional and financial care. Most participants reported that physical care was required the most when caring for their children especially since they are getting older. The following quotes are examples of physical care required by parents when caring for their adult children with intellectual disabilities:

*Participant 3: "No, I can manage to do that but like at home sometimes if she falls, like if I take her in the shower and when I am taking her out, if she has to fall then I need someone to help me pick her up, because she is heavy you know. I can't pick her up on my own that is very challenging."*

*Participant 4: "Because when he sleeps and when he wakes up, then his leg is completely, very weak, I have to hold him to take him to the bathroom."*

*Participant 6: "And then you must know another thing is, when you are younger you've got more energy but now it's very difficult for us as well. Yes it has taken its toll, you can't do this or that, but everything it takes its toll and now you can really feel it. There are days when my husband used*

*to bath him and that, it's very difficult it's not easy, bath him, shave him and all that."*

*Participant 7: "No we shower him, he is use to the shower and he refuses to sit in a bath but when we shower him it is tiring, now I realise that we are getting tired, we have to shower and you have to watch him, he mustn't fall, like the one when he was in hospital I never even told my husband about it and had a fit while I was showering and he fell and I can't lift him because he is dead weight I had to leave him and sit with him till he got control of his body to stand up again."*

*Participant 11: "Yes, I help them to go to the toilet and brush their teeth and when we get their porridge and when we do out baths I help them and dress them and then they come and sit here."*

Dillenburger and McKerr (2010:33, 34) identified that the greatest challenges faced by older parents were their adult children's care requirement, the need to keep them occupied, difficulties in dealing with behavioural problems, general supervision, medical care, future planning and their own health and well-being. Social factors refer to family relationships, socio-economic status and social support (Hatala, 2012:51). The type of care required resorts under the social factors in the biopsychosocial model.

#### **3.8.4.6 Sub-theme 4.6 – Finances**

Most participants reported experiencing financial difficulties especially since they were pensioners. Some of the participants had to source an additional income to pay for special equipment, medical aid, therapies, clothing, food and toiletries for their children. The following quotes are examples of the financial difficulties experienced by the participants of adult children with intellectual disabilities:

*Participant 2: "It is now about 15, 18 years I started doing catering, thank God for that, that is helping me a lot, with her medication, her well-being, her clothes, whatever her needs are. I am doing that for her."*

*Participant 3: "...my husband use to see to the needs and that for three boys and I use to see to hers because it was quite heavy. I did have to at that time because the expenses were high....so I had to do sewing that is why it was getting me down because it was too much running around plus getting all the sewing...."*

*Participant 4: "I am getting one and a half; he is getting one and a half. So that three grand [R3000] we got, we have to pay the girl to do the washing, ironing, the phone I must pay, I haven't got a cell phone. You*

*know all this, by the time, with what you are left over you got about 15 hundred rand left and then that must be pulling us from 9 o'clock tonight for the day, you know you can't eat eggs every day, we don't eat meat every day, but now when we go and buy vegetables it is expensive. It is very difficult [says researcher's name], but the thing is you take it as it comes, like now when he comes from school, 12 o'clock, 1 o'clock what is there to eat, I say no what you want? But just don't ask me luxury food because I can't give, he say make for me egg bread. You know things, small-small things, but then it costs you money so I make sure I have got enough eggs, I got enough butter, I got enough jam and peanut butter because he wants to eat, not every time, but he wants eat, have something."*

*Participant 10: "I haven't yet, I have to now arrange for that to basically take her to the local clinic because I don't think, and the medical aid doesn't pay the funds for the medicines also, all the time...it is becoming a bit of a thing, we are feeling it right now, so yes the grant money does help a lot also."*

A study by Pulusa (2006:69) mentions that "families could not manage to satisfy the financial needs of their [children with a disability] and of the family as a whole." All of the participants reported that their children received disability grants. Parents caring for adult children with intellectual disabilities suffer greater levels of stress, may experience loss of earnings from having to give up work or face additional costs from clothing, bedding, special equipment and medical bills (Molteno, 2007:526). Social factors refer to family relationships, socio-economic status and social support (Hatala, 2012:51). Finances falls under the social factors in the biopsychosocial model.

#### **3.8.4.7 Sub-theme 4.7 – Community reactions**

Some participants reported that some people in the community would stare and make nasty or inappropriate comments. Some of the participants reported that the Indian community was not as understanding compared to other communities. The following quotes are examples of community reactions towards the participants' children:

*Participant 2: "But then with the other culture, like the Whites, the physio, the occupational therapist, her psychologist, no ways, it was very loving, it was comforting, it was welcoming her, there was no distinguishing between her and the other child. It was always with the Indians."*

*Participant 4: "Not the elderly people, elderly people use to just stare at him like they have never saw somebody, and then their children, their grandchildren they all use to stare and look and laugh and all those things. Well the Indian people are like, I didn't know you had a son like this, and you know and I would say look man he is 30 years old man, you people know me for 50 years and now you are telling me something else."*

*Participant 6: "They [Indians] are the worst because I don't say I want sympathy, but they do not understand at all, like if you go with a child that is screaming, you know the Blacks will understand, the most understanding people are the Blacks. They will understand all of that but like the Indians, sorry to say but they are terrible. And then it was like lot of them use to gloat also."*

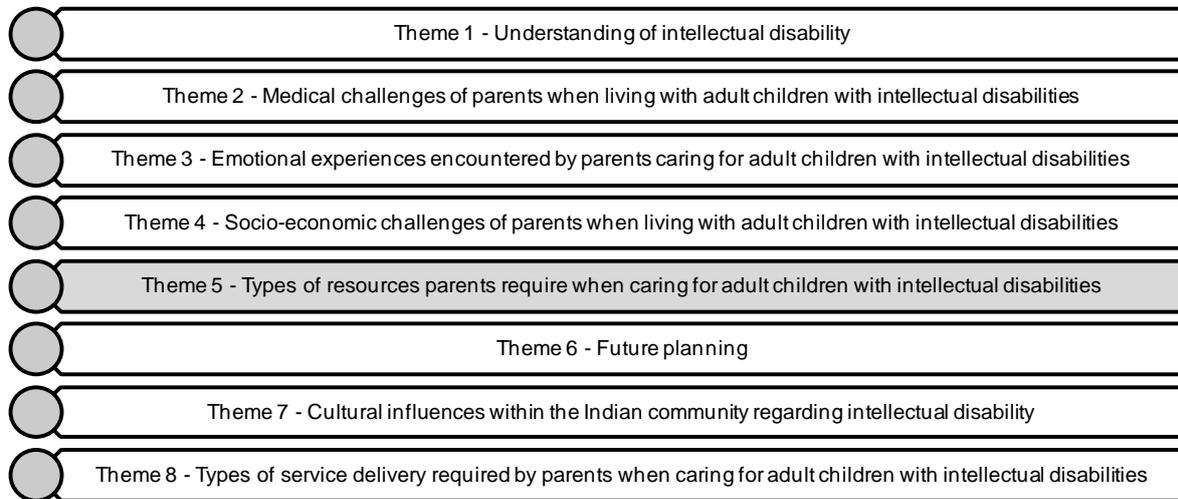
*Participant 7: "You know what, the Whites they've got empathy, they use to come, they'll speak us, they'll ask out but the others would rather stay away or not say anything, or keep quiet maybe in their mind they felt, pity for us, I don't know what goes on, I can't judge them and I don't blame them. It's only the one day I got very angry I think someone the child asked the [Indian] mother, what's wrong with that boy? I was living in the flats here that time, and she said the child is mad that's the only time then I went to her, I tell her you know you must educate your children, or come and ask me first before you call my son names and he is not mad."*

*Participant 10: "No before I had her, then when she came I use to go with her but the [Indian] people use to look and you know how it is, it is a normal thing, in the beginning we felt that why are they are doing that, checking her out and all that but as days went and as time was going I realised but they also want to know what is going on, and yes there were people that if they see me coming they don't want to sit next to me because she use to eat chocolate, she could eat herself, but as in a real 3-month old baby, messing and looking and she is a big girl."*

Werner (2015:460) mentions that people with intellectual disabilities are often negatively affected by stigma, especially by public stigma, "which refers to the attitudes of the general population toward stigmatized persons." The author suggests that public stigma is harmful and has a negative effect on the individuals' inclusion in community life.

Social factors refer to family relationships, socio-economic status and social support (Hatala, 2012:51). Community reactions resort under the social factors in the biopsychosocial model.

### 3.8.5 Theme 5 – Types of resources parents require when caring for adult children with intellectual disabilities



From the participants' responses, it became evident that parents required different types of resources but their biggest need originated from the lack of special schools in the community.

#### 3.8.5.1 Sub-theme 5.1 – Lack of special schools in the community

All the participants reported that initially there were no resources in the community and they had to go outside of the community mostly because of racial segregation. As a result of apartheid, the participants felt that their children could have benefitted more had they received access to essential services. One of the participant's family members was responsible for establishing a special school in the community that had not been available previously due to a lack of resources. From the special school, the special adult workshop was initiated. The workshop only caters for mild to moderate intellectual disability and people with more severe disabilities cannot be assisted. The following quotes are examples of the challenges parents experienced with regards to accessing resources in the community:

*Participant 3: "Everything was outside Laudium, everything was far nothing was in Laudium, that was now so many years back, everything I had to go was quite out of Laudium, I had to drive all the way to right to Menlyn's side. The school she was going to was right at Witbank highway, all the therapies were out of Laudium there was nothing at all in Laudium at that time. No that is the only workshop. I did try initially many years back, but there wasn't any facility available. There were a few workshops I*

*think in Pretoria or something but that also had the stairs and all that so they didn't accept, they didn't have the facilities."*

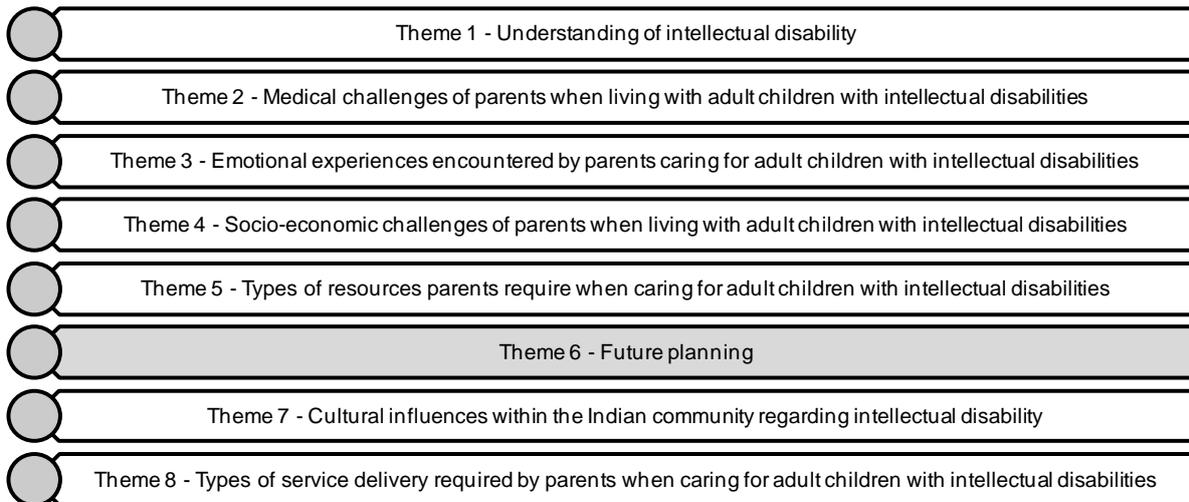
*Participant 4: "No there wasn't, in the apartheid time you know it was very difficult but then you use to get one or two White people, good people, they would talk amongst themselves because I wanted to put him in a school in Villieria, but then the transport was a problem because the time I was working and the time for him to go to school, there was no transport. And I think after 3 months I got reply because he was a non-White they said no there is no place."*

*Participant 6: "No he was very hyperactive and those days, the days of apartheid, we couldn't even take him anywhere. Yes, it was very difficult because in fact there is a school in Menlyn and I think it was one of the speech therapist I had, private, that told me about that but they wouldn't accept non-white children there and I use to take him once a week, I think it was once a week also, as an outpatient for about an hour."*

*Participant 7: "He could have been helped, that's the only thing I think, that time New Hope School, they had segregation there because the colour of my skin, I wasn't accepted. My child needed help. The nurses come home to deliver the medicine but it is also becoming, this year we are having issues in that sense because they don't have medication, so they take their time to come, I have to phone and ask them but that is it, nothing else."*

In a study by Chadwick et al. (2012:125) state that parents of adult children with intellectual disabilities reported receiving poor support from the lack of services such as respite care, home-based and therapeutic support services. People with an intellectual disability have been both severely marginalised and stigmatised on a worldwide scale historically, societally but also through discriminatory policies, laws, actions and inactions by decision makers in all community spheres (Nichol & Adnams, 2016:530). The lack of resources such as special schools in the community is a social factor in the biopsychosocial model.

### 3.8.6 Theme 6 – Future planning



Only two participants were actively concerned about their children’s future. These participants have already made plans in residential/frail care facilities in the event of their death. The one participant even put their child in a residential facility on a trial basis because the facility will not accept people over the age of 40. Some participants reported that they expected their other children would take over the care of their sibling with an intellectual disability, but it was never formally discussed. Other participants reported that they were hoping that their children would die before them. The following quotes are examples of parents’ reaction towards future planning for their children once they are no longer able to provide care:

*Participant 1: “I am getting older, I don’t know what to do. I don’t know what to do if I drop dead tomorrow or now or whenever, what happens to him? Can he live by his own, he can’t. Can he survive? I think it about it every day [says researcher’s name] and I do nothing. I think of it every day, I think it’s, I don’t want to make, I don’t want to do anything about it. I would like him die before me, which of course is maybe not going to happen. But I had to draw up a will and in my will I had to state what happens to him and I have said that the house that we are in now and I have appointed this very woman to sort of give her permission to stay with him in the house, all expenses paid, until his demise then. Other than that, if she can’t, then the executors must appoint somebody else or put him in a home.”*

*Participant 3: “No I don’t think so, they have to look after her, there is no question about that. Ja it is just an unspoken rule, my elder son I think would take care of her. He and his wife and if anything has to happen I think he would take over and then I leave it in God’s hands whatever God*

*decides for her. I hope that we go together. I pray that we go together because I can't imagine anyone else having that patience and the time to look after her. Although they are there to support me and that but if the responsibility would come on them I don't know if they could handle it."*

*Participant 5: "I feel God must take him first but it is in his hands. But God mustn't make him suffer."*

*Participant 6: "Look I mean he is okay now and all that but I just feel, I just pray that he goes before us. That is all, they [the other children] we can look after him, he is going to be with us. I always felt that if my husband goes that I won't manage or that, I don't know how I will manage, but I won't put him away. No they'll look after him, or they'll do what is best at the time, you don't know what the circumstances will be then."*

*Participant 9: "I have bought a unit in a frail care centre...and my daughter says, listen I am not getting married and I will look after them [the other siblings]..."*

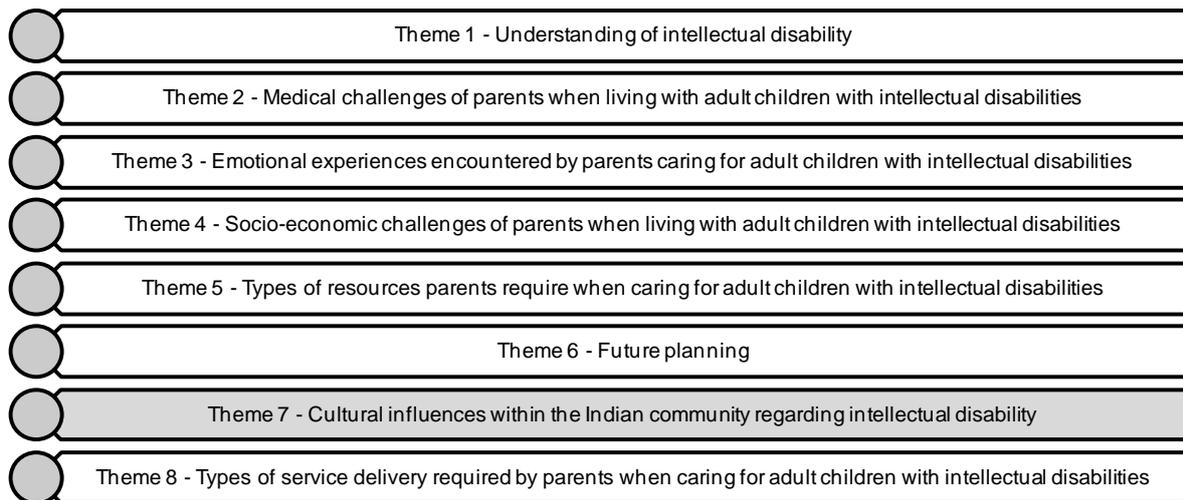
*Participant 12: "No, I want a place for him to be safe, you know in a boarding facility so in future that you know. We have got it already...he is on a trial. In this place, he is on a three months trial. And this place we put him in they have got it's what, it is a long term thing, it is a lifelong thing, if that school still exists. In other words they eventually they had their own frail care. So from there depending if they need frail care, so that is why they don't take them once they reach 40. They don't want over 40. The year they take them must be before 40."*

Parents of adult children with intellectual disabilities continue to provide care into their own old age because of this sense of parental responsibility, which often occurs alongside the belief that there are no alternatives or that alternatives are unacceptable (Cuskelly, 2006:20). Dillenburger and McKerr (2010:30) mention that the question "what will happen when we become unable to care for our child ourselves" is a stressful question faced by older parents of adult children with intellectual disability.

As parents age, there may be involvement of renegotiation of roles within the family in an effort to secure ongoing support and care for the adult child with intellectual disability (Coyle, Kramer & Mutchler, 2014:303). Therefore, most parents prefer and expect that a sibling will assume these responsibilities once the parents are no longer able to provide care (Coyle, Kramer & Mutchler, 2014:303). It becomes vital for siblings as the new caregivers to have access to reliable resources to assist them with their increased responsibilities (Hasman & Zafron, 2010:34).

Social factors refer to family relationships, socio-economic status and social support (Hatala, 2012:51). Future planning resorts under the social factors in the biopsychosocial model.

### **3.8.7 Theme 7 – Cultural influences within the Indian community regarding intellectual disabilities**



Based on the participants' responses with regards to cultural influences within the Indian community, the researcher identified the role of culture on perceived belief system in the Indian community regarding the cultural views of intellectual disability.

#### **3.8.7.1 Sub-theme 7.1 Role of culture on perceived belief system**

The majority of the parents reported that they experienced stigmatisation in the Indian community because of their children with an intellectual disability. This resulted in them being socially isolated from the community. Since the researcher belongs to the Indian community, she can identify with the parents who mention that the preceding generations (parents and in-laws) believed that any illness including intellectual disability is caused by their karma (previous deeds) or is punishment for their sins. Even though these parents did not necessarily believe in those cultural views of their preceding generations, many parents still performed special prayers and rituals and travel to India for ancestral healing with the hope that their children would improve or recover. Although some parents interviewed in the present study reported that although they did not believe in these cultural views, they still felt the psychological impact because of the constant reminder from family members.

Most of the participants reported that culture played a role in how they, their families, (especially in-laws) or the community viewed or understood the reason for their children's intellectual disability. One participant reported that she felt that God was punishing her for her wrong deeds, while other participants reported that their families believed it was their karma that caused them to have a child with an intellectual disability and they had to do special prayers only for the sake of pleasing their families. Some participants believed that having a child with an intellectual disability is a special gift from God and not everyone is as fortunate to be as blessed as they are. The following quotes are examples of what role culture on perceived belief system plays with regards to their children's intellectual disability:

*Participant 1: "I also feel that God is punishing me in this way by giving me my child the way he is because he was conceived out of wedlock and I feel that God just really said, well you have done something wrong and you're going to pay for it."*

*Participant 2: "I think with Indians there is always a stigma to say, you know Indians look at children like these as if there is bad luck or what... Yes. They would look, I don't know I can't say, but my mother-in-law use to say that to me. It is your karma that you got a daughter like this and she remarked that there is nobody in our family like this..."*

*Participant 5: "Everybody can't get it [the privilege of having a child with an intellectual disability]. You see, they say those types of children [children with special needs] they will take you straight in a good place [heaven]."*

*Participant 6: "...because I thought we will do some prayers or whatever... they won't simply want their sons to get married to my daughters for example, things like that, it is still...I think it is a privilege to actually have him. Because they are very special, they are very special."*

*Participant 9: "...they won't say it because one of the things, one of those gara's [bad side effects], the eclipse you are not supposed to be cutting [with a knife], and I was pregnant and they needed me to work in the shop so I was cutting in the shop, so they won't open their mouths. Because someone did say that, but I don't believe in it. What if the eclipse is there and you cut a slice of bread, what that eclipse and cutting the bread got to do with your baby? I did not believe in it."*

*Participant 10: "So it was always because you know you did this or you went, the belief of the old people was that if the one is giving birth the second one cannot go until her months are finished or whatever. Now my sister in-law gave birth and went to go and see the baby that night and after 4 days, I ended up having the baby which I was only going to give*

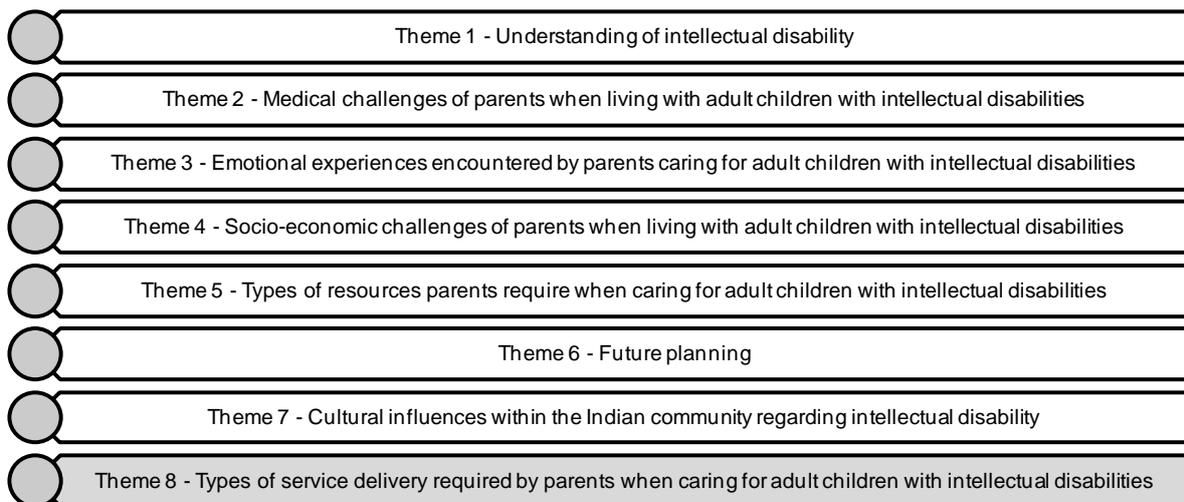
*birth in January, so that, ja, in terms of they believes was the Karma story I can tell you, but I didn't think it serious, because I felt that if almighty want to give me him, gave me and it is my challenge and I have got to this must be out of it, it can never be anything bad...my late mother in-law, may God bless her, and whatever. She always felt that if we don't tell the people there would be benefit for them [the other children] and I felt I need to know, I don't know this child, I understand these things and if I am not going to talk, how am I am going to help myself. I was left I come from where she was from old thoughts and then superstitious and very secretive and I was completely opposite of her. So she couldn't get me right on that way, so yes I use to talk to people and then doctor told me go to Sunrise school, you will see children like them and I went willingly where she wanted me not to go and then her words were this, that nobody will get, no one will come marry [oldest daughter's name] and ..."*

Culture is defined as “the ways in which different societies understand their collective systems of meaning and meaning making, as well as their collective ways of valuing and understanding the world which they inhabit” (Semenya & Mokwena, 2012:72). The following are cultural views and understandings of what causes intellectual disabilities amongst the Indian community (Baxter & Mahoney, 2016):

- A girl is expected to be like her mother and a boy like his father and when this does not occur, it can be seen as a disturbance in the natural order.
- A family may wonder whether their child with a disability has been taken over by a spirit or they see him as a ‘changeling’ (when people believe that a child has been secretly replaced by fairies for the parents' real child during childhood)
- The perceived stigma of having a child with an intellectual disability may make the parents feel isolated from the rest of the community.
- Families may worry that having a child with a disability will affect the marriage prospects of other family members, especially daughters.
- It is believed that intellectual disabilities are caused by “mistakes” made by parents or ancestors.
- Sometimes, the will of God, karma, evil spirits, black magic or punishment for sins may be seen as causes of disability.
- Some of the other reasons that people believe is the cause for an intellectual disability includes: medicines or illness during pregnancy, consanguinity, psychological trauma in the mother and lack of stimulation for the infant.

Corcoran and Walsh (2013:11) mention that “although the biological and psychological levels relate to the individual, the social aspect of the framework captures the effects of the family, the community, and the wider social culture.” Culture forms part of the social factors and therefore it is part of the biopsychosocial model.

### **3.8.8 Theme 8 – Types of service delivery required by parents when caring for adult children with intellectual disabilities**



From the participants’ responses with regard to service delivery, the researcher identified two aspects that highlight the participants’ experience with the services available or the lack thereof. These two aspects relate to the required services for better care of their adult children with intellectual disabilities and the role of professional services.

#### **3.8.8.1 Sub-theme 8.1 – Required services for better care**

Some of the participants reported that the following services which they do not have access to are required to assist them in better caring for their children with intellectual disabilities: Indian residential facilities within the community that cater for their cultural and religious needs, support groups, wheelchair-friendly public transport systems, day care facilities that offer better stimulation, trained caregivers and a drop-off centre where their children can stay for a week. The following quotes are examples of the services required for better care of their children:

*Participant 1: "But you must remember that being a Muslim to go into a home, the food is a problem, things like that. There is no Muslim home that you can send him to, as far as I know."*

*Participant 3: "...if I had a nice little shower where I could roll the wheelchair in it would make it lot easier for me and for her and another thing I would really like to have is transport, a public transport where she can move, you know where a wheelchair can just go onto the bus."*

*Participant 5: "Play...exercise for them, you see. Exercise actually you know..."*

*Participant 6: "...I would be happy if I know there is a place where they'll really look after him, especially the Indian community...it would be nice if there was a place where they could have taken him for a week or two or that so I could get a break."*

*Participant 7: "You see when I went to Canada, but they had a parent group there, I actually wanted to move away that time but you need sponsorship and money and if you have a child like this you have to have money, then only the government lets you in. And I found their system really good like if you, weekends if you needed to go shopping or something there was a parent that would come and help you out. Even the education system, very good."*

*Participant 9: "Yes, in New Zealand they had this...my child use to go on camps with them, camps meaning they took her away for a week then the homes, if you want to go somewhere you can go and leave your child for a week there, not for a whole year or something, like you want to go away for a week or a weekend, they had these facilities... I don't know, have once a week a night out, you know, in a hall organise, even if it is a dance program or whatever where they can just vent out their anger which in New Zealand, every Friday night they could go and, go to the club and they had people working and look these Whites are very into it, you get all these youngsters helping out and they will put music and they will dance and they will stand and they will talk to one another or give one a mic[rophone] and karaoke let him sing. Once a week they had that which was good."*

Bentley and Molteno (2015:612) state that although South Africa has a range of policies that address intellectual disability, budget and resource constraints mean that few policies have been effectively implemented and therefore services for people with intellectual disability tend to be concentrated in large cities and are not accessible to those from rural areas. Many services are provided by non-governmental organisations rather than by the government itself. Corcoran and Walsh (2013:11) suggest that in the biopsychosocial model "...processes within

each level interact, prompting the occurrence of risks for emotional or mental disorders and the propensity toward resilience, or the ability to function adaptively despite stressful life circumstances.” Therefore, working from a biopsychosocial perspective assists in identifying the services required for better care.

#### **3.8.8.2 Sub-theme 8.2 – The role of professional services**

Only a few participants reported that they had received professional services such as psychology and physiotherapy. The following quotes are examples of the role professional services played in parents receiving caring for their children:

*Participant 2: “There were people...There was a professor, psychologist, ja he spoke to me on a one-to-one basis this is what I accepted and this is what the challenges you would face there was a lot of support from them.”*

*Participant 8: “...but [the physiotherapist name] was a great help because she explained to me that it is not in my hands, a miracle can happens and it can happen anytime. And I have done what I could do and if I could not do it, it does not matter, I should not feel guilty. So that was a big encouragement for me, it gave me strength.”*

Social work services play an important role in providing support throughout the different stages of the life cycle. Social Workers play a vital role in meeting the needs of people with intellectual disability because they provide assessment, intervention and advocacy for people with intellectual disability and their families (Robinson et al., 2012:176). Therefore, working from a biopsychosocial perspective assists in identifying challenges that Social Workers can use for improving service delivery to parents and their children with intellectual disabilities.

### **3.9 SUMMARY**

In this chapter, the research methodology for the present study was discussed. Data from semi-structured interviews was collected and analysed in order to identify themes and sub-themes of relevance to the objectives of the study.

The themes and subthemes were identified from the transcripts which acknowledged and represented the challenges and experiences of the participants in the present study. These were substantiated through quotations with the integration of literature

where applicable. The theoretical framework that was used in the present study was the biopsychosocial model. The main themes identified were according to the biological, psychological and social/cultural factors.

In the next chapter, chapter four, the key findings, the conclusions and recommendations of the present study are presented.

## CHAPTER FOUR

### KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 INTRODUCTION

In this chapter, it is explained how the goal and objectives of the study were reached by highlighting the main findings of the present study. Conclusions are drawn from the present study and recommendations are made on the key findings of the present study.

#### 4.2 GOALS AND OBJECTIVES

##### 4.2.1 Goal

The goal of the present study was to explore and describe the challenges of Indian parents caring for adult children with intellectual disabilities. The research question of the study was:

**“What are the challenges of Indian parents caring for adult children with intellectual disabilities?”**

##### 4.2.2 Objectives

The goal was achieved through the attainment of the following objectives:

**Objective 1:** To conceptualise and describe intellectual disabilities in adult children.

This objective was met in Chapter 1 in section 1.1 and in Chapter 2 in section 2.1 and 2.2.

Intellectual disability is a lifelong condition, affecting the person as well as their family at every life stage. Associated health conditions, behavioural problems and co-morbidities further complicates the management of intellectual disability resulting in challenges for parents and siblings caring for adult children with intellectual disabilities. The present study focused on the challenges of Indian parents. Therefore, it explored the role of culture and the cultural views on intellectual disability within the Indian community and contributed towards the understanding of how they view the causes of intellectual disability.

**Objective 2:** To explore and describe the care required for adult children with intellectual disabilities.

This objective was met in Chapter 3 in section 3.8.4.5.

Participants reported that they required various types of care when caring for their adult children with intellectual disability such as physical, emotional and financial support. Most participants reported that physical care was the most important requirement when caring for their children especially since they are getting older.

**Objective 3:** To explore and describe the biopsychosocial challenges of parents caring for adult children with intellectual disabilities.

This objective was met in Chapter 1 in section 1.2, Chapter 2 in section 2.3, 2.4 and 2.5 as well as in Chapter 3 in section 3.8.1, 3.8.2, 3.8.3, 3.8.4, 3.8.5 and 3.8.6.

Parents face many challenges in coping with their adult child with an intellectual disability, which takes a progressive toll on their health and psychological well-being (Song et al., 2014:122). Therefore, the biopsychosocial model was applied in the present study because it allowed for addressing parental inadequacies, loss of employment, educational opportunities, stigma of mental illness, rejection by family, burden of care, destructive and broken relationships and various forms of exploitation and abuse, which are all challenges faced by parents caring for an adult child with an intellectual disability (Smith, 2007:639).

**Objective 4:** To explore the role of culture in caring for adult children with intellectual disabilities.

This objective was met in Chapter 2 in section 2.6 and Chapter 3 in section 3.8.7.

Participants reported that culture played a role in how they, their families, especially in-laws or the community viewed or understood the reason for their children's intellectual disability. Even though these parents did not necessarily believe in those cultural views of their preceding generations, many parents still performed special prayers and rituals and travel to India (for ancestral healing) with the hope that their children would improve.

**Objective 5:** To devise strategies for social work interventions that can broadly promote the well-being of parents of adult children with intellectual disabilities.

This objective was met in Chapter 1 in section 1.2, Chapter 2 in section 2.8 and Chapter 3 in section 3.8.8.2.

Social work is a discipline based upon a strengths-based model of assessment and intervention because all individuals have the capacity for growth and change (Robinson et al., 2012:179). By using this model in the present study, the researcher can devise strategies for social work interventions that could promote the well-being of parents caring for adult children with intellectual disability. Strategies include helping the parent and adult child to seek and develop problem-solving skills, strengthening, coping and developmental capacities, addressing the relationship between the parent/adult child and the systems they interact with and link them with needed resources, providing services and opportunities and investigating the systems seeking to reform them to meet the needs of the parent/adult child more effectively (Zastrow, 2012:45).

### **4.3 KEY FINDINGS OF THE STUDY**

Key findings of the study were as follows:

- The parents did not receive a formal diagnosis for their children with intellectual disabilities. However, they all displayed a fair insight into and understanding of their children's intellectual disabilities.
- Due to the lack of education at the time, technology and medicine associated with intellectual disabilities, parents were given a limited life span prognosis for their children.
- There are many medical challenges for parents when living with adult children with intellectual disabilities such as associated health conditions, co-morbidities and psychiatric disorders. Their children also require medication and therapy to ensure a better quality of life.
- The emotional experiences encountered by parents caring for adult children with intellectual disabilities ranges from positive emotions to negative emotions.

- The parents chose to be self-employed because it offered flexible working hours in order to take care of their children with intellectual disabilities.
- The parents and adult children with intellectual disabilities experienced a lack of a social and community life because of behavioural problems, lack of facilities available as well as stigma within the community.
- The most supportive system parents experienced when caring for adult children with intellectual disabilities is the immediate family members such as spouses and other children.
- The marital and sibling relationships are affected as a result of having an adult child with an intellectual disability. The parents have no privacy and they are not able to spend time together. The siblings experience that they receive less attention from their parents.
- The aging parents require assistance with regards to physical care when caring for their adult children with intellectual disabilities.
- Despite receiving a disability grant, parents required an additional source of income to pay for special equipment, medical expenses, therapies, clothing, food and toiletries for their adult children with intellectual disabilities.
- The parents experienced the Indian community as not being as understanding compared to other communities because they stare and make nasty or inappropriate comments.
- Due to racial segregation, parents could not access special schools in the community for their children with intellectual disabilities.
- The parents hoped that their adult children with intellectual disabilities would die before them.
- The families of adult children with intellectual disabilities believed that cultural influences were the cause of the intellectual disability.
- The parents required the following services which they do not have access to but will assist them better in caring for their children with intellectual disabilities:
  - Indian residential facilities within the community that caters for their cultural and religious needs,
  - Support groups,
  - Wheelchair-friendly public transport systems,

- Day care facilities that offer better stimulation,
- Trained care-givers,
- A drop off centre where their children can stay for up to a week.
- Professional services such as psychologists and physiotherapists play a pivotal role in the lives of parents and their children with intellectual disabilities.

In summary, from the information gathered, it is clearly evident that having an adult child with an intellectual disability has numerous challenges for parents and their families. However, a supportive system and access to relevant resources in the community does assist in overcoming these challenges.

#### **4.4 CONCLUSIONS**

The following conclusions were compiled from the literature review and empirical research findings of the study:

- A formal diagnosis is required for parents and children in order to access appropriate services as well as to understand the disability and the challenges that accompany it.
- It can be concluded that the parents experience many medical and psychological challenges when caring for adult children with intellectual disabilities.
- Parents of children with intellectual disabilities need employment that offers them flexibility so that they and their children have a better quality of life.
- The social and community life of parents and their children are severely impacted as a result of the intellectual disability.
- It is crucial to have access to a supportive system such as families, friends and the community to ensure that both parents and children enjoy the benefits of having healthy relationships and better quality of life.
- Since parents are aging, physical care is needed the most when caring for adult children with intellectual disabilities.
- There are additional costs when caring for adult children with intellectual disabilities that cannot be covered by a disability grant.

- The Indian community is not considered to be supportive towards adult children with intellectual disabilities.
- As a result of apartheid, children with intellectual disabilities could not access essential services such as special schools within the broader community.
- There is a huge gap in service delivery for Indian parents when accessing services, to provide care for their adult children with intellectual disabilities within the community.
- Parents have not actively made plans regarding the care and supervision of their adult children once they are no longer alive.
- Culture does play a role in how parents, their families, in-laws and the community viewed or understood the reason for their children's intellectual disability.
- Professional services are needed for parents and their children with intellectual disabilities to ensure a better quality of life.

#### **4.5 RECOMMENDATIONS**

Based on the key findings and conclusions of the study, the following recommendations were made:

- Medical professionals should always inform parents about their children's diagnosis during childhood and adult children should be reassessed according to the DSM 5. The medication that adult children with intellectual disability receive should be reviewed annually.
- An inter-disciplinary team consisting of Doctors, Social Workers, Psychologists, Occupational Therapists and Physiotherapists should be available to the parents and their children throughout their lifecycle to assist with the various biopsychosocial challenges they experience.
- Parents and families of children with intellectual disabilities should receive information sessions/workshops regarding the intellectual disability and how to overcome the challenges they experience.
- Community involvement should be encouraged and inclusion of people with intellectual disability in the open labour market.

- An Indian residential facility, within the community, that caters for all the religious and cultural requirements/needs is required.
- Drop-off centres are required that relieve parents occasionally and more-wheelchair accessible facilities are needed within the community.
- A support group for parents and siblings should be available at the different life stages.
- Community involvement regarding recreational and extra-mural activities for adult children with intellectual disabilities.
- The community should be educated about mental illness and specifically intellectual disability to prevent stigma and discrimination.

**Policy:** There should be policies that address service delivery issues which cater for all levels of severity of intellectual disability. The caregivers in these facilities should undergo regular staff development training to be able to effectively handle the needs of adult children with intellectual disabilities before receiving their licenses.

**Further research:** This current research project can go one step further and look at the challenges of siblings caring for adult children with intellectual disabilities.

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# APPENDIX A: INTERVIEW SCHEDULE

## SEMI-STRUCTURED INTERVIEW SCHEDULE FOR PARENTS CARING FOR ADULT CHILDREN WITH INTELLECTUAL DISABILITIES

### TITLE OF STUDY

Challenges of Indian parents caring for adult children with intellectual disabilities

### INTRODUCTION

Thank you for agreeing to participate in my study. Before we begin I would like us to go through the informed consent form so that you can get a better idea of why I am doing the research and also about your rights as a participant in my study. (This will be done in case it has not been done prior this interview). If you have any questions at any time, please feel free to ask and interrupt if necessary.

Do you have any questions before we begin?

### SECTION A: PERSONAL INFORMATION

#### 1. Biographic information

Age

Gender  Female  Male

#### Marital Status

Never married (single)  Married  Separated  Divorced  Widowed  Living together/cohabiting

#### Highest educational qualification

Grade 10-grade 12  Diploma obtained at a FET training Institute or college  
 Degree obtained at a university  Post graduate qualification

2. Tell me a little bit about yourself? Just give me a brief description of who you are and anything else that you think I might want to know about you.

- Family background
- Number of children
- Any disability within your broader family

#### **SECTION B: INTELLECTUAL DISABILITY**

3. Tell me what is your understanding of intellectual disability?
4. Tell me does your adult child receive any medication or treatment? What problems you experience regarding this treatment?

#### **SECTION C: REACTIONS TO INTELLECTUAL DISABILITY**

5. Share with me any feelings/emotions you experience as a result of caring for your adult child with intellectual disability?

#### **SECTION D: CHALLENGES OF LIVING WITH INTELLECTUAL DISABILITY**

6. Tell me about the challenges you experience in caring for your adult child with intellectual disability with regards to:
- Employment (work schedule flexibility)
  - Social and community life
  - Support system (immediate family, extended family, neighbours, friends, religious organisations)
  - Family life/relationships
  - Finances
  - Resources in the community
7. Tell me about the challenges you experience concerning your adult child's intellectual disability with regards to their:
- Social activities and developing friendship groups
  - Romantic relationships
  - Community reactions towards them
  - Future aspirations/support
8. Tell me what role do you think your culture plays in caring for your adult child with an intellectual disability?

**SECTION E: SERVICE DELIVERY**

9. Tell me what services are required which you do not have access to, but are needed to assist you in better caring for your adult child with intellectual disability?
10. Tell me what type of care is required when caring for your adult child with an intellectual disability?
11. What suggestions do you recommend that can improve services provided to parents caring for adult children with intellectual disabilities?

Thank you for your time.

We have come to the end of the interview.

Your contribution is much appreciated.

## APPENDIX B: INFORMED CONSENT



UNIBESITHI YA PRETORIA  
UNIVERSITY OF PRETORIA  
UNIBESITHI YA PRETORIA

Faculty of Humanities

Department of Social Work & Criminology

FACULTY OF HUMANITIES  
RESEARCH ETHICS COMMITTEE

### LETTER OF INFORM CONSENT

#### Section A: Research Information

**Title of study:** Challenges of Indian parents caring for adult children with intellectual disabilities.

**Researcher Name:** Fiona Singh

#### Purpose of the study:

I have been asked to participate in a research study exploring the challenges of Indian parents caring adult children with intellectual disabilities. The reason for participating in the study is for the researcher to interview me in order to find out the numerous challenges faced by Indian parents when caring for adult children with intellectual disabilities.

#### Procedures:

If I agree to participate, the following will occur:

I will be required to participate in an interview, in a venue and at a time that suits both me and the researcher. I will be contacted to arrange a place, time and date. The interview will be digitally recorded with my permission and the data from the interview will be transcribed for research purposes. A pseudonym or false name will be given to me and my identity will never be linked to the data or research report. The interview will

take approximately one and half-hours. I understand that there is no right or wrong answer and that the researcher purely wants my opinion. I understand that I will not benefit directly from this study. I will also not be compensated for my participation in this research study.

**Confidentiality:**

I understand that the data collected, which include the digital recordings and the data will be stored in the Department of Social Work and Criminology, University of Pretoria for 15 years. I also understand that my identity will remain anonymous. I also understand that data will be reported in the research report and scientific journals, but will not include any information that can identify me or any participants in this study. If at any point, I experience any difficulties during or after the study, I will contact the researcher, Fiona Singh.

**Please sign the consent form in the next page.**

Kind regards

**Fiona Singh**

**RESEARCHER**

**SECTION B: RESEARCH CONSENT**

I, \_\_\_\_\_ (Full name and surname of participant) hereby acknowledge that I been informed about the research study. I am aware of what is required of me as a participant. I have read and understand how the research process will be followed. I have asked the relevant questions I may have had and I am aware of the confidential nature of the study. As a participant, I also understand that my identity will be kept anonymous. Finally, if at any point I choose to withdraw from the study I understand I will not suffer any negative consequences.

I, \_\_\_\_\_, have read and understood the purpose of this study.

**Participant:**

Name and Surname: \_\_\_\_\_

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

**Researcher:**

I have explained the study to the participant, and provided him/her with a copy of the participant information sheet.

Name and Surname: Fiona Singh

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

## APPENDIX C: ETHICAL APPROVAL



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Ethics Committee

1 July 2016

Dear Prof Lombard

**Project:** Challenges of Indian parents caring for adult children with intellectual disabilities  
**Researcher:** S Singh  
**Supervisor:** Ms NJ Bila  
**Department:** Social Work and Criminology  
**Reference number:** 26026709 (GW20160611HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 30 June 2016. Data collection may therefore commence.

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

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

A handwritten signature in black ink, appearing to read 'Maxi Schoeman'.

**Prof Maxi Schoeman**  
**Deputy Dean: Postgraduate Studies and Ethics**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: tracey.andrew@up.ac.za**

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

Research Ethics Committee Members: Prof MNE Schoeman (Deputy Dean); Prof KI Harris; Dr L Blokland; Dr R Fassel; Ms KT Govender; Dr E Johnson; Dr C Panabianco; Dr C Pabengil; Dr D Reytum; Prof GM Spies; Prof E Tajjard; Ms B Teebe; Dr E van der Klauwer; Mr V Sibole

## APPENDIX D: PROOF OF PROFESSIONAL EDITING



Marianne Hettasch Editing

Marianne Hettasch  
172 Astrid Street, Meyerspark, 0184  
083 666 3988

21 August 2017

To whom it may concern:

This letter is to certify that I have edited the mini-dissertation "Challenges of Indian parents caring for adult children with intellectual disabilities" of Ms Sharita Fiona Singh in August 2017. I have completed a programme in Editing (Editing: Principles and Practice) at the University of Pretoria and provide English language editing services on a freelance basis.

Sincerely



Marianne Hettasch