The experiences of adolescents living with a sibling with a moderate to severe intellectual disability

by

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ABSTRACT

THE EXPERIENCES OF ADOLESCENTS LIVING WITH A SIBLING

WITH A MODERATE TO SEVERE INTELLECTUAL DISABILITY

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Over time, intellectual disability has been mythologised into folklore, religion and culture resulting in patterns of thought, communication, actions, customs, beliefs and values related to intellectual disability specific to particular societies (Smith, 2002 in Edwardraj, Mumtaj, Prasad, Kuruvilla & Jacob, 2010:736). However, data on the perceptions related to intellectual disabilities in the general population, and specifically in the more rural areas are sparse.

The individual with an intellectual disability may have a significant influence on his family members, as he or she may demand specific requirements and obligations of the family members, depending on the severity of the intellectual disability (Moyson & Roeyers, 2012:88). According to Mandleco, Frost Olsen, Dyches and Marshall (2003:365), relatively limited research has explored the relationship between the parents' and non-disabled siblings' functioning when living with an individual with an intellectual disability. The adolescent is in need of healthy support within the family system to help him during his unique process of change. Within families with intellectual disabilities, healthy functioning may be influenced or challenged (Graff, Neely-Barnes & Smith, 2008:240). However, according to Begum and Blacher (2011:1581) research indicates that there seems to be inconsistent findings on the manner in which individuals with intellectual disabilities have an impact on their non-disabled siblings.

Therefore, it was the goal of this study to explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability. The family-

systems theory could provide an appropriate theoretical framework to work from in order to explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability, seeing that the reciprocal influences of different sub-systems was explored. In order to achieve this goal a qualitative research approach was adopted. Applied research was considered the most suitable as the research findings emanating from this study could be used to propose recommendations regarding new problems or strengths identified and potential services that could be of benefit to families with children/siblings with moderate to severe intellectual disabilities. Only the identified non-disabled adolescents participated in this study.

Research was conducted in the Carletonville area, Gauteng Province. The intrinsic case study was employed as the research design. The researcher recruited 10 (n=10) participants through two non-probability sampling techniques, namely purposive sampling, followed by snowball sampling. Semi-structured, one-on-one interviews were conducted to gather rich information from the participants. A pilot study was conducted in order to pre-test the interview schedule's effectiveness. Creswell's process for thematic data analysis was used to extrapolate themes and sub-themes. The trustworthiness of the data interpretation was confirmed through reflexivity, peer debriefing and an audit trail.

The outcome of the empirical study revealed that the participants were unfamiliar with the term intellectual disability and that they demonstrated a limited ability to define intellectual disability as a phenomenon. As a result, they had a lack of knowledge regarding their siblings' functioning, as well as necessary current and future support needed. It seemed as if the lower the socio-economic background of the participant, the less likely he was to have basic knowledge and insight into his sibling's condition and the implications thereof.

It was concluded that the general public seems to have a lack of knowledge regarding intellectual disability as a phenomenon, as participants were of the opinion that the public acted in a discriminative manner towards their siblings and persons with intellectual disabilities.

The experiences of adolescents living with a sibling with a moderate to severe intellectual disability was explored in terms of their emotions; their relationships with their sibling and with their parents; as well as the influence of living with their sibling

in their lives. Amongst other findings, participants experienced that their siblings received more attention or preferential treatment from their parents. As a result, emotions of sadness and anger were experienced. Participants were concerned about their siblings' care and support. They experienced anxiety, stress and guilt regarding their siblings in terms of care and support; therefore their schoolwork was influenced negatively. The siblings with an intellectual disability influenced the participants' lives positively as their understanding of individuals with intellectual disabilities was enhanced. Lastly, participants were in favour of support and educational groups, professional counselling, as well as guidance in terms of coping mechanisms to support them and their families.

The guidelines proposed for practitioners working with families with an individual with moderate to severe intellectual disabilities are the following: Educate parents and family members involved regarding intellectual disability as phenomenon in order to eliminate misconceptions, unrealistic expectations and family conflict; enhance parents' awareness of existing support services in their surrounding communities; implement community awareness projects in cooperation with the existing centres for people with intellectual disabilities in order to empower the community with adequate knowledge regarding intellectual disability. In order to reduce stigma and discrimination associated with intellectual disability, considering the need for support services identified through this research; practitioners should ensure the rendering of therapeutic services, as well as support and educational groups. In rendering these services practitioners can play a role in reinforcing such families' wellbeing, socio-emotional functioning and interpersonal relationships.

KEY WORDS

- Adolescents

- Experiences

- Moderate intellectual disability

- Severe intellectual disability

- Adolescent with intellectual disability

- Sibling without a disability

- Carletonville area

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CHAPTER 1

GENERAL INTRODUCTION AND ORIENTATION

1.1   INTRODUCTION

Intellectual disability is considered as an intellectual developmental disorder (*Diagnostic and Statistical Manual of Mental Disorders* [DSM-5], 2013). People with intellectual disabilities experience complications with daily activities to an extent that reflects both the severity of their mental deficits and their adaptive functioning as well as the extent of the assistance or support they demand. Having a child or sibling with moderate to severe intellectual disability has unique influences on the nuclear family's functioning and may demand unique requirements of the parents and non-disabled siblings (DSM-5, 2013; Govender, 2002:2; Kirst-Ashman & Zastrow, 2007:125). The non-disabled adolescent sibling is in a developmental stage where a variety of changes and challenges occur, which require certain adjustments and mastery of developmental tasks. The non-disabled child's experiences regarding the child with an intellectual disability are often neglected (Berk, 2012:529; Giallo & Gavidia-Payne, 2006:946). The question could be asked how these children are prepared and educated regarding their sibling with intellectual disabilities and what their unique experiences and involvement in such a family are. In order to gain a clearer understanding of the experiences of adolescents living with a sibling with a moderate to severe intellectual disability, these experiences should be explored from the adolescents' own perspectives.

The key concepts for the study are:

Adolescent

Adolescent refers to the child in the transitional period between childhood and adulthood, from about 11 or 12 years until 18 or 20 years (Kirst-Ashman & Zastrow, 2007:226), or from 11 to 13 years, ending at the ages of 17 to 21 years (Louw & Louw, 2014:304). However, adolescence has also been described as a developmental stage beginning at puberty, when the body reaches sexual maturation and ending in society, while meeting societal norms and expectations. These societal norms and expectations may include self-reliance, independence and

the fulfilment of adult roles such as following a career (Louw & Louw, 2014:304). However, for the purpose of this study, the adolescent refers to an individual between the ages of 13 and 19 years.

Nuclear family

A traditional nuclear family refers to heterosexual parents and siblings in a primary family system. Single-parent families and stepfamilies can however also be regarded as nuclear families (Kirst-Ashman & Zastrow, 2007:134-135). DuBois and Miley (2005:364) define a family as the basic unit of society with functional responsibility for childbearing, child rearing, education and socialisation.

Categories of intellectual disability (or intellectual developmental disorder):

Mild intellectual disability

Individuals with a mild intellectual disability may reach grade six by late adolescence, and special education will be helpful. Educational limitations become more evident as they advance in school. They are in need of intermittent support, thus occasional provision of support when required. They are able to be self-supportive in an almost normal fashion and successful in the community, albeit within a stable and supportive environment (Kirst-Ashman & Zastrow, 2007:122; Weiten, 2007:349).

Moderate intellectual disability

Individuals with a moderate intellectual disability are able to develop communication skills during childhood. Their possible expected educational level will be from second to fourth grade by late adolescence, and special education is necessary. They are in need of limited support, as they are semi-interdependent within a sheltered environment, and they need help with even mild stress (Kirst-Ashman & Zastrow, 2007:121; Weiten, 2007:349).

Severe intellectual disability

Individuals with severe intellectual disabilities have limited ability in speech and anything that requires systematic training, for example toilet habits. They are in need of extensive support. Furthermore, they are only able to contribute to self-support under full supervision (Kirst-Ashman & Zastrow, 2007:121; Weiten, 2007:349).

Experiences

The *Psychology Dictionary* [sa] defines experience as "[t]he conscious event; present content consciousness; or an event resulting in learning." Experiences can also be defined as "…something that happens to you that affects how you feel" (*Cambridge Advanced Learner's Dictionary*, 2008:491). Therefore an adolescent living with his[1] sibling who has an intellectual disability has first-hand experience of how it affects him, as it is his reality. Such adolescents' experiences will entail their first-hand knowledge and understanding from their own perspectives and feelings involved which may be of great value within qualitative research.

1.2   THEORETICAL FRAMEWORK

Henderson and Tompson (2011:476), when referring to the family, state that the whole unit is greater than the sum of its parts and that change in any part affects all the others. According to the family-systems theory, the family refers to a living social system that consists of sub-systems. A system refers to a set of elements that form an interrelated and a functional whole. Families are systems, composed of a number of individuals, who are the elements making up the system. Furthermore, a sub-system refers to a secondary system, a system within a system, for example parental and sibling sub-systems. The family-systems theory places emphasis on the interconnectedness of family members, emphasising that when events impact one family member, all members are affected to a certain extent (Graff et al., 2008:240; Kirst-Ashman & Zastrow, 2007:138). Bitter and Corey (2013:397) are of the opinion that the development and behaviour of one family member is indefinitely interconnected with others in the family.

According to Graff et al. (2008:240), researchers focusing on the families of children with disabilities have found the family-systems theory to be a suitable framework for exploring the influence of the disability on the sibling, the sibling-sibling relationships and the parent-child relationships.

The family-systems theory was therefore relevant to this research as it enabled the researcher to improve her understanding of the influence that the sibling with an

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[1] For the sake of brevity, the masculine pronoun is used throughout as the generic pronoun and should be read as including female individuals. No gender discrimination is intended.

intellectual disability has on the family, specifically on the non-disabled adolescent. The family-systems theory could provide an appropriate theoretical framework to work from in order to explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability, seeing that the reciprocal influences of different sub-systems was explored.

1.3   RATIONALE AND PROBLEM FORMULATION

As the youngest child of four, this researcher grew up living with a sibling with a severe intellectual disability. This had a unique influence on her family, her other siblings and her life. Consequently, when working at the Potchefstroom Hospital, the researcher's attention was inadvertently drawn to non-disabled siblings of individuals with an intellectual disability. This was also the researcher's experience during other voluntary work at facilities for individuals with intellectual disabilities. As a result, an interest developed in individuals with an intellectual disability, in adapting to living with a sibling with a severe intellectual disability and in the support available for the non-disabled siblings involved. Fouché and De Vos (2011:84-85) are of the opinion that it is beneficial when the researcher has a personal interest in and is inquisitive about the chosen research topic. The researcher believes that her personal experiences enhanced her interest in and contributed to the completion of a rich and meaningful study.

Although research has been conducted on the effect that a sibling with an intellectual disability has on the non-disabled sibling, Glidden, Hodapp and Kaiser (2005:334) are of the opinion that such research remains underdeveloped. Children's experiences of having a sibling with a disability, in this case an intellectual disability, are according to Stoneman (2009:285), highly variable across families. Similarly, there is extensive variability in psychological and social outcomes for children with a sibling with an intellectual disability. Research regarding the sibling of a child with an intellectual disability includes disability in the broader spectrum, combined with other disorders or sicknesses and/or includes the child with a mild intellectual disability. No research encompasses all the non-disabled adolescents between the ages of 13 and 19 years of one family and living specifically with a sibling with a moderate or severe intellectual disability (Benderix & Sivberg, 2007:400; Dew, Balandin & Llewellyn, 2008:488:493; Giallo & Gavidia-Payne, 2006:937; Graff et al., 2008:261-262;

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Moysen & Roeyers, 2012:87). Limited South African literature was found on the effect that a sibling with an intellectual disability might have on the non-disabled sibling and the latter's unique experiences (Govender, 2002:1).

International researchers have come to different conclusions regarding the need for intervention for children living with a sibling with an intellectual disability. There is no consensus regarding children's need for intervention or treatment participation (Stoneman, 2009:283-284). However, Stoneman (2009:284) concludes that such children living with a sibling with intellectual disabilities may benefit from individual or individual sibling pair intervention or support groups. Therefore, a specific exploration within the Carletonville area regarding adolescents' experiences of living with a sibling with a moderate to severe intellectual disability was of value to gain insight into past and present experiences.

Ms D Grey, social worker at Witrand Hospital, Potchefstroom, counsels the families of outpatients with an intellectual disability, including patients living in the Care Centre of Witrand Hospital on a permanent basis. Grey (2012) is of the opinion that a child with an intellectual disability has unique effects on the family system, parents and especially on the siblings. Although the hospital's focus has been on the child with a disability specifically, support groups have been implemented at this facility. However, no supportive services or educational programmes for siblings exist at Witrand Hospital nor at the Care Centre, or within the larger community surrounding the existing facilities for individuals who have intellectual disabilities. Consequently, the researcher explored the need for intervention for such families with a child/sibling with intellectual disabilities.

The members of a family system are interdependent in order to function effectively. Therefore, a sibling with an intellectual disability has a unique influence on the family's functioning and coping mechanisms (Graff et al., 2008:240). Adolescence is a life phase which can be characterised by change on multiple levels, including physical, emotional and social functioning which can present unique challenges. Additionally, the adolescent living with a sibling with an intellectual disability is required to cope with the unique influences of this sibling on the family system. The non-disabled adolescent himself is in the best position to provide insight regarding his own experiences and perspectives.

Therefore, the research question that guided this research was: What are the experiences of adolescents living with a sibling with moderate to severe intellectual disability?

1.4   GOAL AND OBJECTIVES

1.4.1 The goal

The goal of the research was to explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability.

1.4.2 Objectives

The objectives of the research were:

- To contextualise moderate to severe intellectual disability, as well as adolescence as a life stage.

- To explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability in terms of:

  - their emotions;
  - their relationships with this specific sibling and with their parents;
  - the influence of living with this sibling on their lives.

- To make recommendations for practitioners and to create awareness about the experiences of adolescents living with a sibling with a moderate to severe intellectual disability.

1.5   OVERVIEW OF RESEARCH METHODOLOGY

Qualitative research has at its core the basic assumption that subjective experiences are of great importance. Therefore, qualitative procedures enabled the researcher to explore the phenomenon of the adolescents' unique experiences within the nuclear family, living with a sibling who has a moderate to severe intellectual disability. Such information gathered served as a means for developing a comprehensive understanding of the specific phenomenon (Benderix & Sivberg, 2007:411; Fouché & Shurink, 2011:308).

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The information obtained contributed towards making recommendations regarding new problems or strengths identified and potential services that could be of benefit to families with children/siblings with moderate to severe intellectual disabilities. Therefore, applied research was the most suitable type of research for conducting this study (Fouché & De Vos, 2011:94).

The intrinsic case study design was used to gain information from the adolescents and their unique experiences of living with a sibling with a moderate to severe intellectual disability (Mark in Fouché & Schurink, 2011:321). Research was conducted in the Carletonville area, Gauteng Province. The researcher made use of non-probability sampling, specifically the purposive sampling technique, to identify the participants for the study. Purposive sampling was followed by snowball sampling to identify further participants who met the specific criteria (Babbie, 2005:247; Neuman, 2011:268). A total of ten participants participated in the study.

Semi-structured, one-on-one interviews were conducted to gather rich information from the participants (Berg, 2007:95; Monette, Sullivan & De Jong, 2005:178). In analysing the qualitative data the researcher utilised the process of analysis developed by Creswell (2013), whereby the researcher undertook a thematic analysis of the data (Creswell, 2013:182-183).

All ethical issues relating to the participants of the research, including those that concerned the researcher were taken into consideration during the research. These ethical issues will be discussed in-depth in Chapter 3, of this research report. An in-depth discussion of the research methodology is also presented in Chapter 3.

1.6   LIMITATIONS OF THE STUDY

The following limitations need to be taken into consideration when reading this mini-dissertation:

- Research was only conducted within the Carletonville area, in the Gauteng Province. The research findings regarding the experiences of siblings are therefore not representative of the Gauteng Province as a whole, or of the Republic of South Africa. Findings can therefore not be generalised to these larger populations.

- Since some participants were not well versed in English, they were assisted by an interpreter who acted as a research assistant during the interview. It is possible that the phrasing of words in the process of translation might have deviated, thus contaminating the true feelings and thoughts of the participants. Although the researcher recruited a competent and able interpreter, the possibility of misinterpretation occurring cannot be disregarded.

1.7 CHAPTER OUTLINE

The contents of this research report have been divided into the following chapters:

Chapter 1 comprises of the introduction, contextualisation of the study and definitions of key concepts that were relevant to the study; the theoretical framework of the study; the rationale and problem statement, including the research question; the goal and objectives of the study; a brief overview of the research methodology and the limitations of the study.

Chapter 2 presents the literature overview. An in-depth literature review was undertaken regarding moderate to severe intellectual disability, including the different aspects involved in living with a sibling with a moderate to severe intellectual disability. The influence on the family and especially on the adolescent between 13 and 19 years old was discussed. Unique adolescent developmental characteristics and tasks were included in order to provide an understanding of the adolescent within the context of a family with a sibling with intellectual disabilities.

Chapter 3 comprises of the research methodology, the ethical principles that guided the study and it includes the results of the empirical study, which is integrated with the findings from the literature review.

Chapter 4 presents the key findings, conclusions and recommendations based on the study. In this chapter, the researcher evaluated and discussed the extent to which the study's goal and objectives were met.

CHAPTER 2

THE ADOLESCENT LIVING WITH A SIBLING WITH AN INTELLECTUAL DISABILITY

2.1   INTRODUCTION

Intellectual disability is considered as an intellectual developmental disorder (DSM-5, 2013). People with intellectual disabilities experience complications with daily activities to an extent that reflects both the severity of their mental deficits and their adaptive functioning, as well as the extent of assistance or support they demand. Having a child or sibling with a moderate to profound intellectual disability has unique influences on the nuclear family's functioning and may demand unique requirements of the parents and non-disabled siblings (DSM-5, 2013; Govender, 2002:2; Kirst-Ashman & Zastrow, 2007:125). The non-disabled adolescent sibling is in a developmental stage where a variety of changes and challenges occur, which require certain adjustments and mastery of developmental tasks. The non-disabled child's experiences regarding a sibling with an intellectual disability are often neglected (Berk, 2012:529; Giallo & Gavidia-Payne, 2006:946). The question could be asked how these children are prepared and educated regarding their sibling with intellectual disabilities and what their unique experiences and involvement in such a family are.

Therefore the research question guiding this study is: "What are the experiences of adolescents living with a sibling with a moderate to severe intellectual disability?" In order to answer the above mentioned question, certain objectives must be met. The literature chapter will assist the researcher to gain a better understanding of the specific phenomenon, namely intellectual disability, the specific population, being adolescents, and to explore research on families with a child/sibling with intellectual disabilities.

2.2   DEVELOPMENTAL CHARACTERISTICS OF THE ADOLESCENT

Louw and Louw (2007:279, 230) define 'adolescence' as the transitional period between childhood and adulthood. Depending on biological, socio-cultural factors, including individual differences, the age when adolescence starts as a separate

developmental stage may differ from 11 to 13 years and end between 18 and 20 years. Within the South African context, it is considered that adolescence ends at the age of 18 years when parental supervision expires and the individual can be held accountable for contractual obligations (Children's Act 38 of 2005). For the purpose of this study, the adolescent will refer to a person between the ages of 13 and 19 years.

Geldard and Geldard (2005:4) are of the opinion that the period of adolescence holds a variety of challenges for teenagers because of physiological, biological, psychological and social changes. Crucial processes of change are necessary if these challenges are to be confronted adaptively and successfully. In order to view the adolescent in the context of this study it is important to gain a better understanding of the adolescent and the typical characteristics associated with this particular developmental phase. Therefore the following discussion will focus on the different aspects of development during adolescence.

2.2.1 Physical development

Adolescents find themselves in the phase of puberty which refers to physical transition to adulthood in reaching sexual maturity (Berk, 2009:200). Geldard and Geldard (2005:4) add that puberty refers to the biological events which surrounds the first menstrual cycle in girls and first ejaculation in boys. These events trigger the beginning of a process of profound physical change. This phase is characterised by rapid body growth that includes changes in physical features related to sexual functioning. Primary sexual characteristics refer to changes in the reproductive organs, whilst secondary sexual characteristics refer to outward changes of the body. The puberty process normally begins in general from age 10 until 15 years of age, however the age at which each of these characteristics are attained can vary greatly from individual to individual and according to gender (Berk, 2009:200, 201; Louw & Louw, 2007:283, 284; Rathus, 2006:477).

According to Louw and Louw (2007:285) early and late puberty do not have the same effect on boys and girls. For example, the effects of early maturation are usually positive for boys, as these boys tend to be more popular, have a higher self-esteem and are more assertive whilst often negative for girls, as they tend to become conspicuous, often leading to sexual approaches, deviant behaviour and a

poor body image. Late development in boys are usually notable in them being less attractive, less balanced, more tense and often considered as more immature in comparison to boys that developed earlier. Girls who developed later are usually considered as more attractive, talkative, and more popular and have a better self-image as compared to girls who developed earlier (Louw & Louw, 2007:285, 286; Rathus, 2006:486, 487).

Therefore it is evident that significant physiological changes occur. The adolescent grows in height, weight and strength, develops sexually, and changes in appearance. These physiological changes occur over a period of time and takes place at different ages and rates for every individual. Subsequently, this may cause related issues for the adolescent who may feel self-conscious, awkward and out of line with the rest of his peers who are developing at a different rate and negative feelings may be connected to his appearance (Gerald & Gerald, 2005:5). Berk (2009:200) and Rathus (2006:477) add that puberty profoundly affects psychological development and social relationships as the biological, cognitive, social and emotional functions are being reorganised that will require the adolescent to adapt to these changes. Therefore, the unique changes which the adolescent has to undergo in terms of biological and psychosocial functioning to prepare him for adulthood, is undeniable.

2.2.2 Cognitive development

Stang and Story (2005:6, 7) are of the opinion that the early stage of adolescence is marked by the existence of great cognitive development. In the beginning of adolescence, cognitive abilities are subject to concrete thinking, egocentrism and impulsive behaviour. The adolescent may still regress to more concrete thinking when confronted with overwhelming emotions or stressful situations. During this time the improvement of verbal abilities and conventional morality is traceable, including the adjustment to greater educational demands. During the later stage of adolescence the individual is able to comprehend more abstract and complex concepts.

According to Jean-Pierre Piaget's (1977) theory of cognitive development, the adolescent finds himself in the stage of formal operations, characterised by the capacity of flexibility, reversible operations regarding abstract concepts and scientific

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thinking, such as insight regarding statements and theories. Therefore the adolescent starts to think like an adult. Adolescents are capable of hypothetical-deductive thinking that helps in problem solving; they can anticipate the consequences of their actions; understand logical sequences of events; they are able to understand different views and perspectives on a situation, and are therefore able to take the perspectives of others; they can detect logical patterns or inconsistency in thinking, and they are able to think about changes that happen over time, for example changes over time in relationships (Berk, 2009:251; Louw & Louw, 2007:300; Rathus, 2006:518-520; Weiten, 2007:435). Furthermore, Berk (2012:568-570) makes the statement that adolescents are becoming cognitively and emotionally more mature and developed to think more complexly, to reason and to understand more abstract emotional concepts, compared to younger developmental stages.

Cognitive development can influence a variety of areas in the adolescent's development, including relationships, friendships, school performance and risk behaviour (Louw & Louw, 2007:303). Ackermann (2001:109) states that adolescents will not only strive for independent choice-making, but because of their increasing ability to reason more cognitively, they would also be more critical of their parents' values and perspectives. These cognitive changes can lead to some limitations that may prevent the adolescent from engaging in sound reasoning.

Ferrara (2002:78) is of the opinion that adolescence is a time when the adolescent is most preoccupied and self-conscious. Sometimes adolescents may be incapable of demonstrating certain formal-operations, especially when they are unfamiliar with a particular task. Although adolescents are able to comprehend the ideas of others, they have difficulty in sorting out aspects that concern others from the things that concern themselves. Consequently two common cognitive distortions develop during this phase, namely the imaginary audience and the personal fable. The imaginary audience refers to the adolescent's obsession with his own image, whereby he falsely believes that he is the focus of everyone's attention, like an audience that constantly has their focus on him. Therefore, appearance can become extremely important as well as what others may think. Whereas the personal fable refers to the adolescent's belief that his feelings and thoughts are special and unique and that he

is vulnerable. This cognitive distortion can be considered as an aspect of adolescent egocentrism (Berk, 2009:252; Rathus, 2006:522, 523).

Barnet (2009:1) makes the statement that cognitive development includes the ability of the brain to begin processing more abstract thinking and the challenging search for self-identity. Therefore this developmental period allows the adolescent to search for a sense of self.

2.2.3 Psycho-social development

Geldard and Geldard (2005:8) are of the opinion that the biological and cognitive changes that the adolescent undergoes have a significant influence on the psychological functioning of the adolescent. Psychological challenges emerge which particularly revolve around the formation of a new identity. Failure to achieve a satisfying personal identity is most likely to have negative psychological implications. Stang and Story (2005:6) add that the biological changes that the adolescent undergoes can significantly influence psychosocial development. An increased awareness of sexuality and body image is considered a fundamental psychosocial task during adolescence. A great increase in body shape and size can for example result in ambivalence among adolescents, especially among females, that may lead to the development of poor body image and eating disorders if not addressed. Likewise, a perceived delay in sexual maturation and biological development, specifically among males, may result in the development of poor self-esteem and body image.

Emotional reactions can play a significant role during this phase as well. According to Geldard and Geldard (2005:10) emotional reactivity and high intensity of emotional responses are particularly evident during this phase. This makes it challenging for the adolescent to regulate his behavioural responses, which may result in being overly extreme at times. This emotional instability can often correlate with the adolescent's adaptability and the acceptance of biological changes and body image (Gouws, Kruger & Burger, 2008:117).

Stang and Story (2005:5) state that the adolescent is in the process of developing a stronger acknowledgement of his own identity including the recognition of his own set of moral and ethical values. The adolescent develops a greater perception of

feelings of self-worth and self-esteem. Erikson's psycho-social theory refers to psychological and social development, whereby each developmental stage or phase represents itself as a developmental crisis or conflict that emerges from interaction between genetic and social influences. It would be the ideal to find a balance between these two opposing poles in order to provide ego strength to promote healthy development (Papalia, Olds & Feldman, 2006:29, 30; Weiten, 2007:431). The most important developmental task of adolescents is their search for ego identity, which refers to who they are and what they stand for, according to Erikson (in Rathus, 2006:547).

The adolescent therefore has the task to develop identity, self-acceptance and independence. If indeed the child struggles to master this task, role or identity diffusion may develop which will inhibit the individual to develop successfully in the developmental stages that follow. The child is in need of adequate support and freedom within the family context in his endeavour to develop his own unique personality, social identity, a positive self-concept and self-esteem (Berk, 2012:638, 639; Louw & Louw, 2007:309; Papalia et al., 2006:461; Weiten, 2007:446). Rathus (2006:554) asserts that self-esteem refers to the sense of value or worth that a person attaches to himself. Whilst self-concept refers to the individual's perspective of himself which includes the ideas, thoughts, beliefs and attitude that he might have towards his physical, emotional, social and spiritual existence (Geldard & Geldard, 2012:209; Gouws et al., 2008:98).

Rathus (2006:547) states that adolescents are faced with a variety of questions regarding their sexual orientation, gender-role behaviour and future. The adolescent's ability to engage in formal-operational thinking enables him to make such choices. The adolescent's thoughts are no longer restricted to concrete experiences therefore they can weigh the available options without necessarily directly experiencing them. The adolescent finds himself in a psychosocial moratorium, the stage where the child experiments with different roles, values, beliefs and relationships. The adolescent often finds himself in an identity crisis that refers to the turning point in development where he examines his values and makes decisions about his life roles. However, great uncertainty may develop that can result in for example anxiety, impulsivity and hostility against roles or values (Louw &

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Louw, 2007:309; Papalia et al., 2006:461). Fourie (2001:93) concludes that a negative self-concept may lead to adolescents who:

- are rejected by the peer group;
- manage a low social profile;
- will pursue purposefully to remain popular among the peer group;
- will be influenced easily by the peer group;
- will let the peer group make decisions that will influence them.

In contrast, a positive self-concept can add to the healthy development of emotional welfare, positive social relationships, successful scholastic functioning, including the acquisition of a personal identity (Gouws et al., 2008:117). Rathus (2006:554) is of the opinion that positive development of self-esteem and self-concept during adolescence tends to dip during early adolescence as the young person faces the differences between his real self and his ideal self. However, self-esteem tends to improve with emotional support from family and peers. Therefore it can be concluded that the family and the peer group are fundamental role players in the development of the adolescent's search for his personal identity and convictions.

Stang and Story (2005:6) are of the opinion that peer influence is usually a prevailing psycho-social issue during adolescence. Young adolescents especially are highly aware of their physical appearance and social behaviours in which social acceptance plays an important role. Adolescents' attitudes toward themselves are also based on what they have learned from others, including the peer group (Mwamwenda, 2004:63). Ackermann (2001:106) adds that the psychological impact will determine how vulnerable the child would be for social expectations and rejection by the peer group. Other social risks that might play a determining role in the progressing of vulnerability in the adolescent include the following: adult-adolescent conflict, rejection by the peer group, extreme conformity to the peer group and negative peer pressure (Mash & Wolf in Theron & Dazell, 2006:398). Berk (2012:639) agrees that the peer group plays an influential role in adolescence and that the adolescent especially has the desire to fit in. However, the family remains the most important context for child development in which sibling relationships and child-parent relationships play an influential role. It is foreseeable that the different areas of the adolescent's development are intertwined and that these areas influence each other.

The adolescent is faced with numerous changes and challenges unique to his developmental period.

2.2.4 Moral development

Geldard and Geldard (2005:14) define moral development during adolescence as the manner in which moral matters are perceived. Adolescents increasingly develop the ability to reason more cognitively and complexly which enable them to evaluate others' values and perspectives more critically in order to develop their own value system (Ackermann, 2001:109; Gouws et al., 2008:123). Geldard and Geldard (2005:14, 15) add that the adolescent is able to develop a clearer understanding of what they believe in and stand for. Furthermore they tend to look within themselves in order to examine their own thoughts, feelings and reasoning. It may further cause the adolescent to seek answers to questions of a spiritual nature. The adolescent's spirituality is often demonstrated in a more essential way in his pursuit to find meaning in life's daily experiences.

Gibbs (1995) as quoted by Papalia et al. (2006:444) states that "Piaget maintained that children develop concepts of fairness or justice through interaction with peers", whereas Lawrence Kohlberg was of the view that "all social relationships offer opportunities for social role-taking - taking the perspective of others - and thus stimulate moral development." Kohlberg (in Papalia et al., 2006:444) developed three levels of moral reasoning, wherein the adolescent may find himself; either level two or level three of this theory. Level two refers to conventional morality where the person has internalised the norms of authority figures. It is a priority to please others and to maintain the social order. This level is usually reached after 10 years of age, however many people never move beyond. Whereas level three refers to post-conventional morality which refers to the person who is able to recognise conflicts between moral standards and is able to make his own judgements according to principles of right, fairness and justice. Usually the third level is reached only during early adolescence or older. Papalia et al. (2006:443-445) come to the conclusion that moral development during early adolescence, from age 12 to 15 years, can be referred to as that "[m]oral reasoning reflects increasing awareness of equity and cooperative rule-making." Whilst from 16 to 18 years, relativism may play the main role in moral reasoning, according to Papalia et al. (2006:443-445).

According to Turiel (in Wait, Meyer & Loxton, 2005:172) the transition from conventional to post-conventional goes hand in hand with the development of the adolescent's own identity. In adolescents' quest for their own identity they are also seeking their own moral values and attitudes that will determine their behaviour. The peer group can also play a significant role in terms of this behaviour. According to Piaget (in Louw & Louw, 2007:346) adolescents are exposed to a wide spectrum of moral perspectives and convictions through peer group interaction. Papalia et al. (2006:446) emphasise that parents play a crucial role as well in adolescents developing a healthy moral value system. Parents can contribute to a child's moral development by for example listening to their adolescent, asking their opinions and valuing these opinions. Whereas parents who lecture mainly and who challenge or contradict their adolescents' opinions may inhibit positive moral development.

Psychological development and social relationships are being transformed while biological, cognitive, social and emotional functions and moral understandings are being reorganised. It is evident that the adolescent has to adapt to different processes and changes in multiple facets in his life and development (Berk, 2009:200; Geldard & Geldard, 2005:14, 15; Rathus, 2006:477). The adolescent is in need of healthy support within the family system to help him during the process of change. Although, within a unique family setup where there is a sibling living in the home with an intellectual disability, healthy functioning may be influenced or challenged (Graff et al., 2008:240).

Different aspects regarding adolescent development were discussed in order to gain a better understanding of the participant and the possible influence that living with a sibling with an intellectual disability might have on him. In the following section intellectual disability as phenomenon will be discussed in depth, including the role of the family and the influence of having an individual with an intellectual disability on family members and in this case, specifically on the adolescent in the family.

2.3. INTELLECTUAL DISABILITIES

The American Association on Mental Retardation (AAMR) is now known as the American Association on Intellectual and Developmental Disabilities (AAIDD). The term 'intellectual disability', rather than 'mental retardation', was adopted as it seemed more appropriate in respecting such individuals' equality and dignity.

The World Health Organisation (WHO) is in favour of this term as well (Davison, Johnson, Kring & Neale, 2010:444-445; Kirst-Ashman & Zastrow, 2007:120,121; World Health Organisation, 2010). This researcher agrees that the term 'intellectual disability' respects equality and dignity and is, therefore, the most appropriate to use within the context of this research.

The Diagnostic and Statistical Manual of Mental Disorders-IV placed emphasis on the IQ level when defining intellectual disability. This manual, published by the American Psychiatric Association, provided the criteria for mental retardation or intellectual disability by referring to an IQ of approximately 70 or below (American Psychiatric Association, 2000:41). However, the Diagnostic and Statistical Manual of Mental Disorders-IV has been revised. Intellectual disability (intellectual developmental disorder) is now defined as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The levels of severity for intellectual disability are defined on the basis of adaptive functioning, and not IQ scores, seeing that adaptive functioning determines the level of support required (DSM-5, 2013).

In order to understand intellectual disability and the influence that an individual with an intellectual disability may have on his family system and on the adolescent, it is important to understand the criteria and categories of different levels of intellectual disability; possible causes of intellectual disability; unique challenges involved in having a child with an intellectual disability and the influence on the family and the family members.

2.3.1 The criteria of intellectual disability

In order to diagnose intellectual disability, the following three criteria must be met as outlined in the DSM-5 (2013):

a) "Deficits in intellectual functions (conceptual domain) 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.

b) Deficits in adaptive functioning (social domain) that result in failure to meet developmental and sociocultural 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.

c) Onset of intellectual and adaptive deficits during the developmental period (practical domain)."

Categories of intellectual disability (or intellectual developmental disorder):

Mild intellectual disability

Individuals with mild intellectual disabilities may reach grade six by late adolescence, and special education will be helpful. Educational limitations become more evident as they advance in school. They are in need of intermittent support, thus occasional provision of support when required. They are able to be self-supportive in an almost normal fashion and successful in the community, albeit within a stable and supportive environment (Kirst-Ashman & Zastrow, 2007:122; Weiten, 2007:349). According to the DSM-5 (2013) mild intellectual disability is defined within three domains, namely conceptual, social, and the practical domain, in the following manner:

- Within the individual's conceptual domain, referring to general mental abilities, difficulties will be experienced in learning academic skills, for example reading and writing. Support is needed in some areas to meet age related expectations. In adults impairments can be experienced in abstract thinking and executive function, for example planning, strategising and in short term memory, including efficient use of academic skills, for example reading is impaired. There is a somewhat concrete approach to problems and solutions compared with age-mates.

- Within the social domain the individual is immature in social interactions in comparison with his developing age-mates, such may include communication and language abilities. Furthermore difficulty in regulating emotions and behaviour within the social setting in an age-appropriate fashion may be

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present. Limited understanding of risk factors in social settings and immature social judgement exist.

- Referring to the practical domain, the individual needs some support in more complex daily living tasks when compared to peers. In adulthood support may entail transportation and money management. Recreational skills are similar to peers, however support is needed in well-being and organisation related to work. Individuals generally need support regarding decision making in health care and legal aspects, and to learn to perform a skilled vocation competently. Support in raising a family is typically required.

Moderate intellectual disability

Individuals with moderate intellectual disability are able to develop communication skills during childhood. Their possible expected educational level will be from second to fourth grade by late adolescence, and special education is necessary. They are in need of limited support, as they are semi-interdependent within a sheltered environment, and they need help with even mild stress (Kirst-Ashman & Zastrow, 2007:121; Weiten, 2007:349). The DSM-5 (2013) defines moderate intellectual disability within three domains, namely conceptual, social, and the practical domain in the following manner:

- Within the conceptual domain a definite delay in the individual's conceptual skills is noticeable in comparison with peers. The following delays can be recognised: slower development in language and pre-academic skills develop in preschoolers; for school-age children, progress in example reading, writing and understanding of time occurs slowly across the school years; for adults, academic skill development is usually at an elementary level, and support is required for all use of academic skills in work and personal life. Ongoing daily support is required to complete conceptual tasks of day-to-day life, and others may take over these responsibilities fully for the individual.
- Distinct differences within the individual's social and communication behaviour in comparison with peers are indicated. Although successful friendships and romantic relationships can be experienced in adulthood, the individual may not perceive or interpret social cues accurately and have limited

communication skills which may influence relationships. Significant social and communicative support will be required in work settings for success.

- The individual will be able to accomplish basic activities within the practical domain, however an extended period of teaching and time is needed. This may involve basic personal care for example eating, dressing, elimination and hygiene and participation in household tasks as an adult. Independent employment in jobs that require limited conceptual and communication skills can be achieved, however considerable support from colleagues, supervisors, and others is needed to manage social expectations and responsibilities such as scheduling and money management.

Severe intellectual disability

Individuals with severe intellectual disabilities have limited ability in speech and anything that requires systematic training, for example toilet habits. They are in need of extensive support. Furthermore, they are only able to contribute to self-support under full supervision (Kirst-Ashman & Zastrow, 2007:121; Weiten, 2007:349). The DSM-5 (2013) defines severe intellectual disability within three domains, namely conceptual, social, and the practical domain in the following manner:

- Within the conceptual domain attainment of conceptual skills is limited. Generally little understanding of written language or of concepts involving for example numbers and time exists. Extensive support is needed in problem solving throughout life.

- Regarding social aspects, the individual's spoken language is quite limited in terms of vocabulary and grammar. Speech and communication are focused on the here and now within everyday events. Language is mainly used for social communication rather than for explanation and simple instructions or gestures may be understood by the individual.

- Within the practical domain, support is needed in basic daily tasks for example dressing, bathing and eating and supervision is needed at all times. Responsible decision-making regarding well-being of self or others is non-existing. Ongoing support and assistance is needed for the adult in tasks at home, recreation, and work. Skill attainment in all areas involves long-term teaching and ongoing support.

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Profound intellectual disability

Individuals with profound intellectual disability require pervasive support, which is more continuous and consistent. These individuals possess little or no speech ability, they cannot be toilet-trained, they need assistance in bathing and eating, and they are rather unresponsive to training. Furthermore, they are in need of total care and pervasive support for survival (Kirst-Ashman & Zastrow, 2007:122; Weiten, 2007:349).

The DSM-5 (2013) defines profound intellectual disability within three domains, namely conceptual, social, and the practical domain as follows:

- Conceptual skills usually involve the physical world rather than symbolic processes. Certain visual-spatial skills can be obtained for example by sorting objects according to physical characteristics. Furthermore objects may be of use in a goal-directed manner during work or self-care. Albeit co-occurring sensory and motor deficits may prevent efficient use of objects.

- Referring to social aspects, the individual has a limited understanding of symbolic communication in speech or gesture to a great extent and may only understand simple instructions. Desires and emotions are mostly expressed through nonverbal and non-symbolic communication. The individual enjoys relationships with well-known significant others, and initiates and responds to social interactions by means of gestural and emotional cues. Co-occurring sensory and physical impairments may prevent several social activities.

- Within the practical domain, individuals are mainly dependent on others for all aspects of daily physical care, health, and safety. However, they may be capable in participating in some of these activities. Individuals without severe physical deficits may assist with some simple tasks at home, for example 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. Leisure time may be spent on, for example listening to music and watching movies, or participating in water activities, with others' support. Co-occurring physical and sensory impairments are often barriers to participation (beyond watching) in home, leisure, and vocational activities. Maladaptive behavior is present in a significant minority.

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The characteristics of all four categories of intellectual disability were outlined above to provide an overview of intellectual disability and existing levels of severity. However, in this study the focus is on individuals with a moderate to severe intellectual disability.

Adnams (2010:437) is of the opinion that there are several factors that may contribute to a child having intellectual disabilities. These causes of intellectual disability will be discussed in the following section.

2.3.2 Intellectual disability within the South African context

According to Adnams (2010:437) no reliable data exists on the causes of intellectual disability in South Africa. However the primary causes of intellectual disabilities can be identified in approximately 25% of those affected. These primary causes may include: genetic or chromosomal abnormalities causing the child to be born with intellectual disabilities; infectious diseases, for example mother-to-child transmitted HIV and AIDS; car accidents, causing brain damage; and environmental factors. There seems to be evidence for an association between poverty and intellectual disability. However, as in other developing countries there is little available data on the mechanisms through which poverty and disability affect each other. However the extent to which the parents are well educated regarding their child's condition can be affected by poverty, lack of services and education (Adnams, 2010:437; Barker, 2004:175; Davison et al., 2010:447, 448).

Adnams (2010:436) identifies a greater prevalence rate of intellectual disabilities in low-income countries versus high-income countries. Research indicates that within the South African context the causes of intellectual disabilities in 20.6% of cases result from congenital conditions, thus either present at birth or inherited, 6.3% because of acquired causes and in 73.1% the causes were undetermined. Thus, it would be difficult to determine the cause of the intellectual disability in all cases.

According to Adnams (2010:439) estimable improvements and progress in South African policy and legislation development and in various governmental and nongovernmental practices have been made. However, there appears to be marked inequities in human rights and access to care and services that exist for a large

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number of individuals with intellectual disabilities in spite of such developments. Adnams (2010:439) further concludes that failures in adequate policy implementation and service delivery, and the low priority of intellectual disability, continue to result in unmet social, health and educational needs in South Africa. For example education policies have not been implemented for those with severe and profound intellectual disabilities, and in practice this group is excluded from governmental educational benefits. It appears that there are service gaps especially for adolescents and adults with intellectual disabilities. This gap extends to literature that has been published on services for individuals with intellectual disabilities, other than organisational reports. The great lack of sufficient services for individuals with intellectual disabilities may set great challenges for these individuals with intellectual disabilities, including their families involved.

Adnams (2010:436) states that the specific cause of the condition will influence the severity of the intellectual disability and have unique implications and challenges for the family system. Therefore, a child with an intellectual disability may have a significant influence on other family members, including the nuclear family system as a whole (Moyson & Roeyers, 2012:88). This influence on the family system will be discussed in the following section.

2.4 INFLUENCE OF INTELLECTUAL DISABILITY ON THE FAMILY SYSTEM

Family functioning encompasses a variety of care-giving functions, including nurturing and socialising children, providing material and emotional support and assuming general responsibility for the well-being of all the members (Kirst-Ashman & Zastrow, 2007:134,135). Different researchers and resources have different opinions regarding the influence that a person with an intellectual disability may have on his family's functioning and consequently on his parents and non-disabled siblings (Blacher & Baker, 2007:330; Govender, 2002:32; Stoneman, 2009:256,258). In order to understand the possible influence that the parents and non-disabled siblings involved may experience, the typical challenges and positive aspects have to be explored.

2.4.1 The influence on the family as a whole

Kirst-Ashman and Zastrow (2007:134,135) are of the opinion that family members need to be able to depend on each other when necessary. Family members, failing to meet their role requirements may cause breakdowns in family functioning. Individuals with special needs, such as those with intellectual disabilities or challenges can place extraordinary role demands on family members. However, according to Stoneman (2009:256) earlier research from written parent narratives and oral life stories consistently included benefits to families with an intellectually disabled child. According to them, parents were effectively rearing children with intellectual disabilities within healthy, well-functioning families (Stoneman, 2009:256). However, Stoneman (2009:285) is of the opinion that the influence that the individual with an intellectual disability has on the family's functioning may be highly variable across families.

Research done by Blacher and Baker (2007:330) focused on understanding positive, as well as negative influences of a child with an intellectual disability on the family as it leads to a more balanced view of such families and of disability as phenomenon. According to research done by Stainton and Besser (in Blacher & Baker, 2007:331) parents in 17 different families were interviewed. The researchers explored main themes, for example source of joy and happiness, source of family unity and closeness, source of personal growth and strength. Similarly, Hastings and Taunt (in Blacher & Baker, 2007:331) conducted a study with parents with a child with an intellectual disability and they explored the possible positive impact that the child with an intellectual disability could have on the siblings and on the extended family. Parent responses included having increased sensitivity and forbearance, improved family dynamics and a changed perspective on life. In effect, having a child with an intellectual disability may be regarded as adding a positive dynamic to the family's functioning. However, Blacher and Baker (2007:331) are of the opinion that although reports from such studies have some heuristic value in identifying themes of possible special benefits, positive bias could have had an influence and without using adequate control groups, these special benefits might be questionable.

2.4.2 The influence on the parents

The child with an intellectual disability may demand specific requirements and obligations of the family members, depending on the severity of the child's intellectual disability. Such a child may often impose on his parent or parents the burden of care, of specialised knowledge, of patience and control (Kadushin & Martin, 1988 in Dubois & Miley, 2005:365).

According to Mandleco et al. (2003:365), relatively limited research has explored the relationship between the parents' and non-disabled siblings' functioning when living with an individual with an intellectual disability. Developmental models of parenting indicate that parents are the primary managers of a family's emotional climate. Therefore, parents' well-being is important for the maintenance of a positive family climate. Greater problem behaviour by a child significantly predicted both more parenting stress and lower efficacy in mothers. Research studies on national and international levels have indicated that emotional stress experienced by parents is unavoidable due to the constant physical care, financial demands and restrictions placed on their normal lifestyles, as well as the disappointment of having a child with a disability. Feelings of guilt arising from their anger and possible rejection of the child could be experienced. Concerns may surface about the future and life-long care of the child with an intellectual disability, especially in the case of a child with a more severe intellectual disability.

Blacher and Baker (2007:333, 343, 344) conducted two research studies on intellectual disabilities. The first study was conducted with Latino and Anglo mothers of 282 young adults with moderate to profound intellectual disability and the second study included both mothers and fathers of 214 young children with mild to moderate developmental delays of typical development. The main aim was to examine the sturdiness of the phenomenon of positive impact in such families and to gain information on the role of the specific child and parent characteristics. According to their findings, positive views and expressions reflected their participants' cultural beliefs related to disability, family and religion. They concluded that parents' views on the positive impact and the behavioural problems that the individual with the

intellectual disability displayed were directly correlated to negative experiences, amongst others, with parenting stress.

Furthermore, raising a child with an intellectual disability can compromise the quality of the marital relationship, as the disability may increase family stress resulting in dissatisfying and challenging marital relationships (Mandleco et al., 2003:370; Govender, 2002:32). If indeed the parent or parents experience extra stresses, this may as a consequence intervene with warm, involved parenting and interfere with children's adjustment in any phase of development (Woolfolk & Perry, 2012:621). However, if indeed the parents' views and cultural beliefs related to disability, family and religion are more positive, their experiences of related challenges of their child with the intellectual disability may be more positive and therefore then be influenced more positively (Blacher & Baker, 2007:344).

Consequently, the family needs to adapt to accommodate the child with intellectual disabilities to ensure the best interest of this child. Parents live with the responsibility to manage their family and raise the non-disabled child/children, in this case the adolescent, and the child with an intellectual disability in such a manner as to function most effectively within the family context. Therefore, although the child with an intellectual disability and the parents may experience multiple difficulties, the non-disabled adolescent may experience inherent struggles under such circumstances as well (Govender, 2002:2; Moyson & Roeyers, 2012:88).

2.4.3 The Influence on the non-disabled siblings

According to Giallo and Gavidia-Payne (2006:946), non-disabled children's experiences will vary in accordance with their developmental stage and the severity of the intellectual disability of their sibling. Therefore, it will be more suitable to restrict the ages of children and the ranges of the sibling's intellectual disability when studying the experiences of non-disabled children. Seeing that adolescents are cognitively and emotionally more mature and developed to think more complexly, to reason and to understand more abstract emotional concepts, they may be able to provide richer and more meaningful information regarding present and past experiences of living with a sibling with an intellectual disability (Berk, 2012:568-

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570). Therefore, the focus of this research is on the experiences of the adolescent who lives with a sibling with an intellectual disability.

The members of the family system are interdependent in order to function effectively. Therefore, a sibling with an intellectual disability has a unique influence on the family's functioning and coping mechanisms (Graff et al., 2008:240). In referring to the adolescent, the peer group and the desire to fit in play an especially important role. Although the peer group is influential during this phase, the family remains the most important context for child development in which sibling relationships and child-parent relationships play an influential role (Berk, 2012:639). Adolescence is a life phase that can be characterised by change on multiple levels, including physical, emotional and social functioning which can present unique challenges. Additionally, the adolescent living with a sibling with an intellectual disability is required to cope with the unique influences of this sibling on the family system.

When a child is born with moderate to profound intellectual disability, adjustments may be needed by the mother and father, as well as the non-disabled siblings in the family. The psychosocial impact on siblings may vary depending on a range of cultural, social and psychological factors. The psychosocial impact can be defined as the effect of having a sibling with intellectual disabilities on the psychological functioning of the non-disabled child. Psychological functioning mainly refers to the emotional and social development, the adjustment and the self-concept of the individual (Dew et al., 2008:486, 489). According to Rathus (2006:554) self-esteem refers to the sense of value or worth that a person attach to themselves. The development of a healthy self-esteem and self-worth plays a significant role during adolescence and tends to improve with emotional support from family and peers. If indeed the family with a sibling with an intellectual disability experiences unique demands and stressors, negatively influencing the family's functioning, support from the parent or parents rendered to the non-disabled adolescent, it may greatly impair the support that he requires in his process of developing a strong self-esteem (Berk, 2012:638-639; Papalia et al., 2006:461).

A qualitative study by Moyson and Roeyers (2012:98) has been conducted in Flanders, Belgium, on the quality of life of siblings of children with intellectual disabilities between the ages of six and 14 years. These siblings felt that they could

not always do, or were not allowed to do what they wanted to because of their siblings' disabilities, thus indicating barriers 'to doing'. The siblings also indicated barriers 'to being', by identifying concerns regarding the reactions of the outside world, being laughed at or bullied because of their sibling with an intellectual disability. Further studies have indicated that non-disabled children experienced stress in coping with public reactions and discrimination towards their sibling, for example staring and making unpleasant remarks (Dew et al., 2008:500). Such actions may lead to potential difficulties in relationships between siblings, especially in the case of severe to profound intellectual disability, accompanied with physical defects. The non-disabled child or children may be affected negatively within a family where the sibling with an intellectual disability attacks family members, continually cries or screams, destroys property and/or throws tantrums at home and in public. Such behaviour may cause weariness, social isolation and frustration or result in depression which may inhibit positive functioning (Benderix & Sivberg, 2007:400,401; Govender, 2002:35; Graff et al., 2008:239). With regard to the adolescent siblings, such experiences related to reactions from the public may cause great difficulty because of the typical limitations in their psychosocial and cognitive development where the adolescent's self-image plays a significant role seeing that they are overly sensitive to what others may think (Berk, 2009:252; Rathus, 2006:522-523).

However, as stated earlier Stoneman (2009:256) has determined that earlier research from written parent narratives and oral life stories consistently included benefits to families with an intellectually disabled child. According to them, parents were effectively rearing children with intellectual disabilities within healthy, well-functioning families. Focusing on the strengths, such benefits for the non-disabled siblings may include the opportunity for expanded role enactments and a chance to educate and support them. Therefore, it may be expected that these benefits may also have the outcome of increased sibling competencies and self-esteem (Stoneman, 2009:256).

The development of a child's self-concept plays an important role during adolescence. Self-esteem tends to improve with emotional support from family and peers. Within a supportive family the adolescent can receive the necessary support and adequate freedom to develop his own unique personality, social identity, a

positive self-concept and self-esteem. Furthermore, he can be able to develop a healthy moral value system and moral understanding (Papalia et al., 2006:446, 461; Rathus, 2006:554; Weiten, 2007:446). Rathus (2006:554) considers the family and the peer group as fundamental role players in the development of the adolescent's search for his personal identity and convictions. However, adequate and healthy support of the family and parents may be prohibited if there are other stressors on the family. A child with an intellectual disability, especially of a more severe nature, may play a significant role placing unique demands and challenges on the family. If indeed the adolescent had not developed a positive self-concept, a negative self-concept may inhibit him to develop a strong sense of self and to function optimally, for example on emotional and social level (Fourie, 2001:93). Nevertheless, Glidden et al. (2005:336) conclude from their research encompassing numerous studies regarding siblings of persons with intellectual disability that one could explore how the experiences of growing up as a child with a sibling with an intellectual disability has either helped or hindered that child's life. One could also explore how it influenced the child's degree of empathy or life views, generally.

There is extensive variability in psychological and social outcomes for children with a sibling with an intellectual disability. Research regarding the sibling of a child with an intellectual disability includes disability in the broader spectrum, combined with other disorders or sicknesses and/or includes the child with a mild intellectual disability. No research encompasses all the non-disabled adolescents between the ages of 13 and 19 years of one family and living specifically with a sibling with a moderate or severe intellectual disability (Benderix & Sivberg, 2007:400; Dew et al., 2008:488:493; Giallo & Gavidia-Payne, 2006:937; Graff et al., 2008:261-262; Moysen & Roeyers, 2012:87). Limited South African literature was found on the effect that a sibling with an intellectual disability might have on the non-disabled sibling, specifically on the adolescent, and the latter's unique experiences of the disability (Govender, 2002:1).

2.4.4 The need for support of non-disabled siblings

Families raising children with intellectual disabilities tend to face challenges above and beyond those faced by non-disabled children. These challenges may relate to factors such as increased problem behaviours shown by children with intellectual disabilities, increased exposure to poverty, stigma, and social exclusion. For many

families, and especially for families in low- and middle income countries, these challenges will be worsened by the absence of sufficient and proper services and supports (Families Interest Research Group of IASSIDD, 2014:425).

International researchers have come to different conclusions regarding the need for intervention for children living with a sibling with an intellectual disability. There is no consensus regarding children's needs for intervention or treatment participation (Stoneman, 2009:283-284). However, Stoneman (2009:284) concludes that such children living with a sibling with intellectual disabilities may benefit from individual or individual sibling pair intervention or support groups. Grey, a social worker at a medical facility for persons with intellectual disabilities in the Potchefstroom area, works with the families of outpatients with an intellectual disability, including patients living in the care centre on a permanent basis. Grey (2012) is of the opinion that a child with an intellectual disability has unique effects on the family system, parents and especially on the siblings. Although the care centre's focus has been on the child with a disability specifically, support groups have been implemented at this facility for the parents. However, no supportive services, for example therapeutic services or educational programmes for siblings exist at the facility nor at the care centre, or within the larger community surrounding the existing facilities for individuals who have intellectual disabilities, including their families.

Edwardraj et al. (2010:746) advise that public awareness, education and community-level intervention are necessary for reducing misconceptions and stigma related to intellectual disability in order to improve the attitude towards and management of intellectual disabilities. As a result families with intellectual disability will be affected positively.

According to research conducted by Govender (2002:26-27) in a rural area of Zululand, South Africa, on the attitudes of parents regarding their children with intellectual disabilities, considerable cultural and religious variations in family members' reactions towards these children exist. Since cultural beliefs help determine whether people view behaviour as normal or abnormal, parents from different cultures might judge unusualness from different perspectives. Thus, the parents' attitudes may affect the non-disabled child's perspective towards his sibling with an intellectual disability. Therefore, parents' and siblings' attitudes towards the

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child with an intellectual disability play an important role in the search for improved services for families of children with intellectual disabilities.

The experience of the child with a sibling with an intellectual disability can be influenced by different factors. As stated by Stoneman (2009:264) numerous researchers concluded that the child's gender, the family size, the relative birth order and spacing of the non-disabled and intellectually disabled child, race, social class, family form, including single parent or both parents, socio-economic factors and cultural expectations must be taken into account. Families often have more than one non-disabled child. However there has been no definite accord on how such variables may affect the sibling relationships at a later stage as adults. It would be impossible to moderate all the mediating variables within a family system (Dew et al., 2008:502; Begum & Blacher, 2011:1587; Glidden et al., 2005:335).

2.5 CONCLUSION

To conclude, the effect of having a child with a moderate to severe intellectual disability has unique influences on the nuclear family's functioning and may demand unique requirements of the parents and non-disabled adolescents involved. Living with a sibling with a moderate to severe intellectual disability may have multiple negative influences on the adolescent's life. However, the sibling with an intellectual disability may contribute to the non-disabled child's development of empathy, responsibility and other positive strengths in due time (Benderix & Sivberg, 2007:400, 401; Govender, 2002:2, 35; Graff et al., 2008:239; Stoneman, 2009:256, 283, 284). Although the situation may contribute to positive life experiences and learning, the adolescent could be unaware of this due to his lack of knowledge, development and support. The adolescent finds himself in unique developmental transitions which may add to his unique experience and perceptions of living with his sibling with a moderate to severe intellectual disability (Berk, 2012:529).

The following chapter will encompass a discussion of the research methodology applicable to the study, as well as the empirical findings regarding the experiences of adolescents living with a sibling with a moderate to severe intellectual disability, as well as the interpretation of these findings.

CHAPTER 3

RESEARCH METHOLDOLOGY AND EMPIRICAL FINDINGS

3.1 INTRODUCTION

In this chapter the research methodology that was used in conducting this study will be explained comprehensively. The empirical findings regarding the experiences of adolescents living with a sibling with a moderate to severe intellectual disability, as well as the interpretation thereof, will be discussed.

The focus of this chapter will be on the following research objective: To explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability in terms of:

- their emotions;
- their relationships with this specific sibling and with their parents;
- the influence of living with this sibling on their lives.

In the following section a presentation of the research methodology applied in this research is outlined.

SECTION A: RESEARCH METHODOLOGY

The research methodology will be discussed by focusing on the research approach that was followed, the type of research that was applied, the research design and the research methods that were used in this study. Furthermore, the ethical considerations relevant to the study will be explained.

3.2 RESEARCH APPROACH

McRoy (in Fouché & Delport, 2011:65) makes the statement that the qualitative research approach aims to understand social life and the meaning that people attach to everyday life. Consequently, it lends itself to ways and methods to explore and gather experiential material regarding the participant's own perception and understanding of his unique situation and world. Such information gathered could serve as a means for developing a rich and comprehensive understanding of the specific phenomenon (Benderix & Sivberg, 2007:411; Berg, 2007:2).

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Kumar (2005:12) refers to the qualitative approach as a more unstructured approach that is suitable when exploring the nature of a phenomenon. The qualitative researcher was therefore privileged to gain a deeper understanding by exploring the reality from the perspective of the non-disabled adolescent living with a sibling with a moderate or severe intellectual disability (Fouché & Shurink, 2011:308).

Qualitative research thus has at its core the basic assumption that subjective experiences are of great importance. Therefore, by using qualitative procedures, the phenomenon of adolescents' unique experiences within the nuclear family, of living with a sibling who has a moderate or severe intellectual disability was explored.

3.3   TYPE OF RESEARCH

Applied research is focused on the scientific planning of induced change in a troublesome situation and therefore, concerned with the solution of problems (Fouché & De Vos, 2011:94). The unique relationships, emotions and experiences of adolescents living with a sibling with an intellectual disability and the need for further support from the adolescent's perspective could therefore be explored by means of applied research.

The information obtained could contribute towards making recommendations regarding new problems or strengths identified. In addition, value could be added regarding the development of educational programmes and/or support groups for the adolescents involved. Thus, the research study has the potential to provide valuable information and recommendations for professionals working with families with a child or adult with an intellectual disability. By means of recommendations, possible problems or needs that might be identified can be addressed in future, supporting the basis of applied research from which this study was derived (Blaiki, 2010:49; Neuman, 2011:27).

3.4   RESEARCH DESIGN

The main interest of a qualitative researcher is to understand a specific phenomenon according to the subjective experiences of research participants (Fouché & Schurink, 2011:308). The intrinsic case study design is a type of case study often undertaken

to gain information regarding a specific phenomenon. The intrinsic case study aims to describe this phenomenon (Yin, 2003 in Fouché & Schurink, 2011:321).

The exploration of a social issue or population (experiences of adolescents living with a sibling with a moderate to severe intellectual disability) took place by means of detailed data collection methods, involving an in-depth analysis of more than one case (Mark in Fouché & Schurink, 2011:321). Therefore, this case study allowed for exploration, better understanding and insight regarding the experiences of adolescents living with a sibling with a moderate to severe intellectual disability. Within the qualitative approach, the intrinsic case study consisted of a small number of cases (10 individuals) in the specific category described (Mark, 1996 in Fouché & Schurink, 2011:321).

3.5   RESEARCH METHODS

In obtaining information on the experiences of adolescents living with a sibling with a moderate to severe intellectual disability the researcher employed various methods and techniques as shall be discussed in the following paragraphs.

3.5.1 Study population and sampling

Research was conducted in the Carletonville area, Gauteng Province, by means of interviews with adolescents from ten families, depending on saturation, who are living with a sibling with a moderate to severe intellectual disability (Monette et al., 2005:242). These families were identified from Rotalia, a centre for individuals with intellectual disabilities. All the families with a child, diagnosed with a moderate or severe intellectual disability, attending the identified centre therefore formed the study population. The facility caters for the needs of learners from all racial and socio-economic groups.

Permission to conduct the research was obtained from the centre for individuals with intellectual disabilities in order to gain access to Black, White or Coloured families of individuals with a moderate to severe mental disability who have a non-disabled adolescent sibling or siblings living in the Carletonville area (See permission attached as appendix A). Only the identified non-disabled adolescents participated in this study and therefore no research was conducted with the disabled siblings or

their parents. Furthermore, no personal files were consulted in this process. Relevant information regarding the research process was discussed with the governing bodies involved, which included the goal and objectives of the research, the focus of the semi-structured interviews and the fact that information obtained was strictly used for research purposes (Mouton, 2001:244).

Purposive sampling, as a non-probability sampling type, had been used in the selection of the participants. This permitted the researcher to select the sample on the basis of predetermined criteria. The principal of the centre assisted the researcher to identify families with individuals in the centre who have an adolescent brother or sister at home, who could be selected for involvement in the research. No personal files were reviewed in this process (Babbie, 2005:247; Berg, 2007:44; Grinnel & Unrau, 2008:153; Monette et al., 2005:148; Neuman, 2011:268).

The researcher selected the sample according to specific criteria for the purpose of exploring the adolescent's experience of living with a sibling with a moderate or severe intellectual disability. The sample for the research consisted of ten adolescents (a brother or sister of the individual in the centre) who met the following selection criteria:

- The adolescent could be either male or female.
- The adolescent could be from any racial group.
- The adolescent must live within a nuclear family with a sibling, aged 15 to 24 years, with a moderate or severe intellectual disability.
- The adolescent must be between the ages of 13 and 19 years.
- The adolescent must be able to understand and express himself/herself in either English, Afrikaans or Setswana.

The researcher aimed to obtain participants by means of purposive sampling, depending on the availability of potential participants who met the selection criteria. Participants, identified by the administrative staff of the centre, who met the above-mentioned criteria, were included in the study. However, as ten adolescent siblings could not be identified, the snowball sampling technique was utilised to identify further potential participants who met the criteria specified above. This technique

was used until a sufficient number of participants, who were willing to participate, had been selected for the study (Alston & Bowles, 2003:90).

3.5.2 Data collection

Children's experiences of having a sibling with an intellectual disability are highly variable across families. Similarly, there is extensive variability in psychosocial outcomes for children with a sibling with an intellectual disability. Although there have been most interesting and informative research questions on understanding this variability both over time and across families, these important research questions do not necessarily require comparison groups (Stoneman, 2009:285). Thus, the researcher aimed to obtain information regarding adolescents' experiences of living with a sibling with a moderate to severe intellectual disability by exploring the adolescents' own perspectives and views regarding this phenomenon.

Semi-structured, one-on-one interviews were used to obtain data and were considered a flexible method according to Greeff (2011:351). Interviews were conducted with ten adolescents between the ages of 13 and 19 years who live in a family with a sibling (between the ages of 15 and 24 years), who has been diagnosed with an intellectual disability. The interviews were conducted by the researcher in a central office at the Suid-Afrikaanse Vrouefederasie (SAVF) in Carletonville (See permission attached as appendix B). An interview schedule with predetermined questions was compiled to guide the interviews (Greeff, 2011:352) (Attached as appendix C). The interview schedule was useful to engage the participant and determine the narrative terrain. The questions used could reflect awareness of the adolescent's understanding and experience of his world in varying ways. Thus, the world was approached from the non-disabled adolescent's perspective, enhancing the possibility of gathering rich information (Berg, 2007:95; Monette et al., 2005:178).

The interview was conducted according to the adolescent's age and understanding. The researcher aimed to communicate on the level of the specific adolescent by taking language and concepts used into account. It was important that the participant understood the researcher in order to provide the most relevant information (Berg, 2007:95,103). The interviews were audio recorded with the purpose of providing text

versions for data analysis purposes. Furthermore, in using audio recordings, the quality and reliability of the information gathered by means of the interviews were enhanced by ensuring that responses were coded accurately (Benderix & Sivberg, 2007:312). The services of an interpreter were used where participants struggled to describe their experiences in English. The interpreter played a valuable role during the interviews, as the participants were able to express themselves in their home language. Therefore, richer data could be obtained.

3.5.3 Data analysis

According to Creswell (2013:182), data collection, data analysis and report writing are not separate steps in the process but rather interrelated phases that take place simultaneously. Creswell (2013:182-183) developed a data analysis spiral process whereby the researcher engages in an analytic circular system rather than working from a linear approach. During data analysis, the researcher made use of the following steps, developed by Creswell (2013:182-188):

3.5.3.1 Organising the data

The spiral process starts during the phase of organising the data or transcribing it (Creswell, 2013:182). The researcher organised the data and converted it into appropriate text units from digital recordings in electronic format and organised the raw data into usable information that was more explicable for analysis (Babbie, 2008:415; Creswell, 2013:182; Schurink, Fouché & De Vos, 2011:408). The researcher made her own interview transcripts as this provided the opportunity to develop emergent insights regarding the findings, as advised by Schurink et al. (2011:408). In addition, the researcher made electronic backup copies of the information in order to prevent loss of data.

3.5.3.2 Reading and writing memos

According to Creswell (2013:183), it is necessary to obtain a sense of the whole database. Before the researcher could provide a thorough interpretation of the findings, the starting point was to read and reread the gathered data in order to gain a clear and comprehensive view and understanding (Schurink et al., 2011:409). To this end, the researcher wrote memos of the transcripts that helped in the process of exploring the database (Creswell, 2013:183). Memo writing enabled the researcher

to formulate ideas and comments on her understanding, own experiences and feelings during the interview process (Schurink et al., 2011:409).

3.5.3.3 Describing, classifying and interpreting data into codes and themes

The central part of qualitative data analysis can be considered as category formation by forming codes or categories, according to Creswell (2013:184) and Schurink et al. (2011:410). The researcher analysed the data by building detailed descriptions and by extracting and labelling the main themes and sub-themes in order to identify patterns and persistent ideas. The broad data could, therefore, be broken down into different themes and sub-themes so that it was more manageable and understandable to present in the final report (Creswell, 2013:186; Schurink et al., 2011:411). The researcher especially made use of abbreviations of key words to label or code the specific themes and sub-themes, as directed by Schurink et al. (2011:411).

3.5.3.4 Testing emergent understandings and searching for alternative explanations

During this phase of data analysis, it was important to appraise the data for its value and centrality. Therefore, the researcher evaluated the significance of certain aspects not found in the data, also referred to as negative evidence (Schurink et al., 2011:415). According to Kreuger and Neuman (2006) in Schurink et al. (2011:415), such negative evidence might have, for example, included a central issue to the research of which the population was unaware; events that the population wanted to hide or misinterpret in order to either protect themselves or others; and the influence of the researcher's preconceived ideas that might have prevented the researcher from noticing opposing facts.

3.5.3.5 Interpreting and developing typologies

Schurink et al. (2011:416) refer to interpretation as the process of making sense of the data. A valuable aid during this process was the development of typologies for sorting different concepts. In this regard, Schurink et al. (2011:416) define a typology as a theoretical structure whereby phenomena are classified in terms of the common characteristics that they share with other phenomena. Therefore, the researcher interpreted the data by categorising and making conceptual linkages between

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different phenomena regarding the unique experiences shared by the adolescents living with a sibling with a moderate to severe intellectual disability.

3.5.3.6 Presenting the data

Data analysis was finally presented in written format during the last phase. The researcher made use of visual images and propositions that signified the linkages between information (Schurink et al., 2011:416).

Schurink et al. (2011:419) are of the opinion that the credibility and reliability of a study are achieved by accurate representation of a participant's perspectives, including a truthful reconstruction of such by the researcher. Therefore, data analysis was done by the researcher personally which was beneficial as the researcher had obtained insight and contextual knowledge regarding the overall research (Litosseliti, 2003:85). It was important that the researcher remained meticulous in dealing with the data throughout the study, from the process of collecting data by means of interviewing, through to the storage of data and the analysis of findings (Creswell, 2009:191; Lietz, Langer & Furman, 2006:445).

The researcher attempted to establish trustworthiness by ensuring that the findings reflect the information received and meanings described by the participants as closely as possible (Lincoln & Guba, 1985 in Lietz et al., 2006:444). In order to enhance trustworthiness, the researcher implemented peer debriefing as a strategy, whereby the researcher engaged in dialog with other professionals outside the research project who were familiar with the topic and the research population (Lietz et al., 2006:451). A professional colleague of the researcher reviewed the researcher's analysis of the transcripts and provided her professional input and critique to make the researcher's interpretations more trustworthy.

The researcher made use of member checking whereby the participants were allowed to review findings of the data analysis in order to confirm the accuracy thereof. This in effect, enhanced trustworthiness, as advised by Lietz et al. (2006:453). Furthermore, member checking was an important strategy to enhance trustworthiness as it provided greater recognition of the participants' experiences and views, lending authority to their perspectives and, therefore, negating the threat of bias (Padget, 1998 in Lietz et al., 2006:453). The researcher reflected on her own

subjectivity and how she had used and monitored this in her research project, as advised by Creswell (1998) in Glesne (2006:37).

3.5.4   Pilot study

A pilot study was conducted in order to pre-test the interview schedule's effectiveness before it was used for the actual semi-structured, one-on-one interviews with the participants. The schedule had been critically examined by the researcher's supervisor and a professional who works with individuals with intellectual disabilities and their families. The purpose was to adjust and correct any poorly phrased questions, or any offensive, emotion-laden wording. Furthermore, an adolescent with similar characteristics as the participants in the main study were interviewed in order to determine how effective the interview was conducted and whether relevant information could be obtained by means of the interview schedule (Berg, 2007:105; Strydom & Delport, 2011:395).

3.6   ETHICAL CONSIDERATIONS

In conducting this study, the researcher took ethical issues into consideration that related to the participants of the research, as well as those that concerned the researcher. The following ethical principles were relevant to this study:

3.6.1   Informed consent

After permission to conduct the research was obtained, sampling was done and potential adolescents were identified. The parents of potential participants were contacted telephonically. A meeting was scheduled to discuss the research in order to obtain informed consent. The researcher informed participants and their parents of the main purpose and objectives of the research, how information will be obtained and that information would be strictly used for research purposes. Furthermore, the researcher informed them that interviews will be digitally recorded for the purpose of data analysis. Before interviews were conducted, informed assent was obtained from the participants. The research process was explained in an understandable manner according to the adolescent's developmental level, respecting his rights and acting with his/her best interests in mind. The parents and the participants were required to sign a letter of informed consent (see attached as appendix D) and informed assent

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(see attached as appendix E) respectively (Blaiki, 2010:31; Neuman, 2011:149-150; Struwig & Stead, 2004:67; Strydom, 2011:118).

3.6.2 Deception of participants

The researcher aimed to avoid possible deception of and false expectations by parent(s) or participants by providing a thorough explanation during the process of obtaining informed consent and assent from the participants and their parent(s). Therefore, the researcher explained the rationale for the study clearly as well as how information obtained might be beneficial for further use in the development of educational programmes and support for the non-disabled adolescent in the family with a child with a moderate or severe intellectual disability (Babbie, 2008:68; Rubin & Babbie, 2010:259).

3.6.3 Voluntary participation and avoidance of harm

'Voluntary participation' and 'no harm to participants' were included in the informed consent letters. The participants were informed that they are taking part in the research voluntarily and that they are at liberty to withdraw at any time if they wished to do so. The parents and participants were informed that the researcher guarded against the occurrence of emotional harm. However, they were also informed about possible issues that could be triggered during the interview. The researcher had assured them that they would be referred to a social worker at the SAVF, Carletonville, free of charge, if they were in need of therapeutic services (Berg, 2007:78; Neuman, 2011:148-150; Rubin & Babbie, 2005:71).

3.6.4 Violation of privacy and confidentiality

The researcher protected the participants' privacy by providing assurance that no identifying details, including names, surnames, contact details or addresses, will be mentioned at any stage during the research process or in the research report. Any information received was used for research purposes only, and privacy and confidentiality were respected and protected (Berg, 2007:79; Neuman, 2011:152-153). As mentioned, the services of an interpreter were used where participants struggled to describe their experiences in English. The interpreter played a valuable role during the interviews, as the participants were able to express themselves in

their home language. The interpreter was required to sign a confidentiality agreement to ensure the privacy and confidentiality of participants (see attached, as appendix F).

3.6.5 Debriefing

Debriefing takes place after data gathering and refers to sessions during which participants are given the opportunity to work through their experiences and have possible questions answered. Debriefing sessions were conducted by the researcher herself. By means of debriefing immediately after each interview with a participant, they were afforded the opportunity to discuss their experiences and express their feelings regarding the research. Debriefing could further prevent misconceptions that the participant could have developed, which may cause harm later on (Strydom, 2011:122).

3.6.6 Publication of findings

Participants should be informed about the findings without violating the principle of confidentiality (Strydom, 2011:126). Therefore, findings will be released in such a manner that it can be useful to others, keeping the ethical consideration of privacy in mind.

Ethical clearance to conduct the research was granted by the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria. (See ethical clearance attached as Appendix G).

The researcher outlined the research methodology applied in undertaking this study namely; the research approach, the type of research, research design, research methods and the ethical considerations. In the following section, the research findings and the interpretation of the data will be discussed.

SECTION B: EMPIRICAL FINDINGS AND INTERPRETATION

The research findings will be presented in two different sections, namely:

Section 1: The biographical profile of the participants

Section 2: The discussion of research data in the format of themes and sub-themes.

3.7 SECTION 1: THE BIOGRAPHICAL PROFILE OF THE PARTICIPANTS

Biographical information was collected from the ten participants who were interviewed. Six of the participants were male, while four participants were female.

Table 3.1: Biographical profile of the participants

Participant	Age	Gender	Race	Home Language	School Grade	Age of sibling with an i.d	Family composition
1	13 yrs	Male	White	Afrikaans	Grade 7	18 yrs	Participant, grandmother, mother and sibling with an i.d
2	13 yrs	Male	White	Afrikaans	Grade 6	14 yrs	Participant, grandmother, father, mother and sibling with an i.d
3	16 yrs	Female	White	Afrikaans	Grade 10	14 yrs	Participant, father, mother and sibling with an i.d
4	19 yrs	Female	Black	Xhosa	Grade 11	15 yrs	Participant, twin sister, mother, sibling with an i.d
5	14 yrs	Male	Black	Xhosa	Grade 5	15 yrs	Participant, stepfather; mother; sister (6 months) and sibling with and i.d

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Table 3.1: Biographical profile of the participants (continued)

Participant	Age	Gender	Race	Home Language	School Grade	Age of sibling with an i.d	Family composition
6	12 yrs	Male	Black	Xhosa	Grade 5	15 yrs	Participant, mother, father and sibling with an i.d
7	14 yrs	Male	Black	Setswana	Grade 8	17 yrs	Participant, father and sibling with an i.d
8	14 yrs	Female	Black	Setswana	Grade 7	12 yrs	Participant, mother, sibling with an i.d and aunt's child of 6 years old.
9	12 yrs	Female	Black	Setswana	Grade 7	17 yrs	Participant, grandmother, father and sibling with an i.d
10	13 yrs	Male	Black	Xhosa	Grade 7	18 yrs	Participant, mother, father, brother (18) and his girlfriend, and sibling with an i.d

As indicated in Table 3.1, the average age of participants were 14 years, while the average age of their siblings with an intellectual disability was 15.5 years. Three of the participants were Afrikaans speaking, while three were Setswana speaking. Four participants spoke Xhosa as a first language. All participants were however able to understand and express themselves in either English or Setswana, which made interviewing possible. All participants still attended school and lived with their sibling with an intellectual disability. The participants' family compositions varied as outlined in table 3.1.

3.8 SECTION 2: THEMES AND SUB-THEMES

In this section the data gathered during the semi-structured, one-on-one interviews with the ten participants will be presented. The information obtained was categorised in five themes and subsequent sub-themes as outlined in table 3.2 below.

Table 3.2: Themes and sub-themes

THEMES	SUB-THEMES
Theme 1: Intellectual disability as a phenomenon	1.1 Perceptions of the concept intellectual disability 1.2 Perceptions of the public's view of intellectual disability as a phenomenon
Theme 2: The functioning of a sibling with an intellectual disability	2.1 Perceptions of challenges experienced by a sibling with an intellectual disability 2.2 The role of the parent(s) in the sibling's daily functioning 2.3 The role of the adolescent in the sibling's daily functioning 2.4 Future support needed for the sibling with an intellectual disability
Theme 3: Relationships within the family	3.1 The relationship between the sibling with an intellectual disability and the parent(s) 3.2 The relationship between the participant and the sibling with an intellectual disability 3.3 The influence of the sibling with an intellectual disability on the participant's relationship with his parent(s)

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Table 3.2: Themes and sub-themes (continued)

Theme 4: The influence of the sibling with an intellectual disability on the participant's functioning	4.1 The influence of living with a sibling with an intellectual disability on the emotional functioning of the participant
	4.2 The influence of living with a sibling with an intellectual disability on the school related performance of the participant
	4.3 The influence of living with a sibling with an intellectual disability on the social life and friendships of the participant
Theme 5: The need for support systems	5.1 The need for support groups for the participant / for family members
	5.2 The need for professional counselling for the participant / family members
	5.3 The need for educational programmes on intellectual disabilities
	5.4 The need for additional coping strategies

The above themes and sub-themes will be discussed and substantiated with literature, as well as verbatim quotations from the interviews. In theme 1 intellectual disability as a phenomenon will be discussed. In order to prevent repetition 'the siblings with an intellectual disability' will be referred to as "the sibling" or "their siblings".

Theme 1: Intellectual disability as a phenomenon

Over time, intellectual disability has been mythologised into folklore, religion and culture resulting in patterns of thought, communication, actions, customs, beliefs and values related to intellectual disability specific to particular societies (Smith, 2002 in Edwardraj, Mumtaj, Prasad, Kuruvilla & Jacob, 2010:736). Nevertheless, data on the perceptions related to intellectual disabilities in the general population, and specifically in the more rural areas are sparse.

The data obtained lead to different understandings of intellectual disability that will be discussed in the following sub-theme.

Sub-theme 1.1: Perceptions of the concept intellectual disability

Intellectual disability as a phenomenon was not clearly comprehended by all the participants, especially by participants from rural areas. Intellectual disability was perceived by them as a learning problem, referring to poor reading and writing skills specifically. According to Adnams (2010:437) the extent to which the parents of children with an intellectual disability are educated regarding their child's condition can be affected by poverty, lack of services and education. This lack of knowledge and insight might also influence the participants' knowledge of intellectual disability as phenomenon. Some participants expressed their views on intellectual disability in the following manner:

"She is a slow learner.''

"Ma'am at school she's good, ne, but she can't write and when the teacher talks, she can understand. But when the teacher asks to spell the words she can't and she can't write."

After exploring what specifically is meant by a 'slow learner', it became clear that the participant refers to learning slower than other children, therefore being on a lower academic level than peers her own age. Participants therefore explained that intellectual disability implied that their siblings were only slow in learning, mainly referring to their struggle in terms of reading and writing. Kirst-Ashmann and Zastrow (2007:121), as well as Weiten (2007:349) indicate that special education is necessary, as the possible expected educational level of persons with moderate intellectual disabilities are from second to fourth grade by late adolescence. As indicated in the DSM-5 (2013) regarding the criteria for individuals with moderate and severe intellectual disabilities, the participants were able to recognise these symptoms in their siblings since they identified that they were slower in learning and development in terms of academic skills, referring to reading and writing.

Other participants in the study were able to perceive that intellectual disability refers to a delay in years on different levels of functioning and that such a disability implies special needs. Intellectual disability as a phenomenon was perceived in the following manner:

"...soos wat 'n normale mens soos in kan hardloop, swem soos in gewone goeters doen, sukkel hulle soos bietjie om dit te doen…Hulle sukkel, soos hulle, party sukkel met loop en

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hulle verstaan nie soos gewone mense verstaan nie." / ["When you struggle to do for example running, swimming, like they struggle to do the usual things that a normal person can do. They find it difficult to walk and they don't understand like normal people understand"]

..."hulle is maar net 'n paar jaar agter…my sussie is nou 14, maar sy het die verstand van 'n sesjarige." / ["They are just a few years behind." "...my sister is now 14, however she has the intellect of a six year old.]

The statements above indicate that the participants could comprehend that intellectual disability refers to a developmental delay and that their siblings cannot understand or do the things that people without an intellectual disability are able to do. These participants were able to acknowledge aspects of a developmental delay in their siblings' intellectual and adaptive functioning, described by the DSM-5 (2013).

Sub-theme 1.2: Perceptions of the public's view of intellectual disability as a phenomenon

Participants in this study explained that individuals from the general public stereotype intellectual disability and tease their siblings by making use of name calling. The participants voiced their opinions on how the general public regards their siblings with an intellectual disability, in the following manner:

"*Sometimes they say 'you are a slow learner; you are a slow learner' and that hurts her so much."*

"They're talking wrong things about him…They're making jokes about him…They're saying he is crazy....Because he's in Boiteko school"

''Sometimes they are teasing her. They say her school is Boiteko…they say when her school is Boiteko, she is "dom".

"Verstandelik gestremdheid is as mense dit hoor dan dink hulle dis 'n aansteeklike siekte; dis dood ernstig en hulle hardloop weg en hulle dink hulle kinders gaan dit kry." / ["When people hear about intellectual disability they think that it is a contagious disease; it is deadly serious and they run away and they think that their children will get it"]

Studies have indicated that non-disabled children experience stress in coping with public reactions and discrimination towards their sibling with an intellectual disability,

for example reactions such as staring and making unpleasant remarks (Dew et al., 2008:500). It was evident that the participants were upset by the negative remarks and labelling by the public and the misperceptions that the public have about their siblings.

Stang and Story (2005:5) state that the adolescent is in the process of developing a stronger acknowledgement of his/her own identity including the recognition of an own set of moral and ethical values. Therefore the participant in his adolescence is able to recognise and acknowledge warped ideas and inappropriate reactions by the public. The participants could state with confidence that the public had a lack of knowledge about individuals with intellectual disabilities and that their reactions towards such persons were unacceptable.

Some participants stated only that the community is fond of their siblings. These participants shared the following views:

"They think she's a good lady, because she respects other people."

"...Some of them they think that he is very clever."

"Ahm hulle dink sy's oulik. Ja oor haar personality en hoe sy praat....die way in hoe sy partykeer goed sê…soos byvoorbeeld sy sal die hele tyd goed herhaal..." / ["They think that she is nice. Yes because of her personality and how she speaks....In the way that she sometimes says things....she will for instance repeat things the whole time."]

The responses by the participants indicate that they experience that the public perceive their siblings in a positive manner only. However, these participants also struggled to define intellectual disability as a phenomenon. In theme two, the participants shared their views regarding the functioning of their siblings in terms of challenges and the support that their siblings need.

Theme 2: The functioning of a sibling with an intellectual disability

Individuals with intellectual disabilities experience unique challenges due to their developmental delay. Therefore these individuals require unique care and support from their parents, as well as their siblings. The following sub-themes will focus on the challenges those siblings with intellectual disability experience and the role of the parents and the participants in supporting them.

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Sub-theme 2.1: Perceptions of challenges experienced by a sibling with an intellectual disability

Participants described that their siblings experience two types of challenges: challenges of an intellectual nature, and also physical challenges.

The participants shared with the researcher that their siblings cannot read and write. Some of the participants regarded their siblings as mainly having scholastic problems, because of their inability to read and write. The following was stated:

"...at home there is nothing that she struggles with, it is only at school. Can't read and write."

"...Can read and write a few words..."

"...Slower, needs support in reading and writing."

Furthermore, the participants expressed the view that their siblings struggled to understand complex concepts and words. Therefore they have to speak in a basic manner in order for their siblings to understand them. The participants stated the following:

"...at home she's fine, but she can't understand every word..."

"Like maybe she don't know all the words, she don't understand some people. If may be she need some help."

Persons with moderate and severe intellectual disabilities often struggle to read and write as their academic abilities are limited and a difficulty in comprehending complex words and conversations exists. From the above statements it is evident that the participants recognised their siblings' intellectual challenges. As described by the DSM-5 (2013) individuals with moderate intellectual disability indicate slower development for school-age children, and progress in language skills such as reading, writing, and academic skill development is usually at an elementary level. A definite delay in their conceptual skills exists in comparison with peers; slower development in language is noticeable. In terms of severe intellectual disability, the DSM-5 (2013) indicates that they have limitations within the conceptual domain in the attainment of conceptual skills and generally little understanding of written language exists.

Regarding physical challenges, the participants expressed the view that their siblings find it difficult to walk and also struggle with the use of their hands due to physical disabilities. The following statements are evidence to this:

"Ja tannie, hy loop amper, soos sy een voet loop so skuins, hy loop nogals ongemaklik." / ["Yes, he almost walks, like one foot walks skew. He walks kind of uncomfortable."]

"In the hands and also the body."

Participants further stated that their siblings needed support in bathing and toilet training, as they struggled to clean themselves thoroughly. The participants also shared the view that their siblings struggled to dress themselves. The participants stated the following:

"Hy sukkel soos as hy badkamer toe moet gaan.... soos die afvee storie.... soos as ons stort, jy moet hom net 'n bietjie help om die water reg te kry, maar hy kan self soos sjampoo vat en sy lyf was." / ["He struggles when he like goes to the bathroom....like with the wiping exercise …when we shower, then he must be helped a little to get the water right, but he can use shampoo and wash his body by himself."]

"...She can bath herself but not very clean."

"...Hy sukkel nogals om sy klere aan te trek." / ["He struggles to dress himself."]

"....Wearing his shoes and wearing his clothes like properly. Like taking off his school clothes, he struggles to put on his normal clothes…he wears them in the wrong place…the right one there and the left there."

From the above it seems clear that the participants' siblings struggled with bathing, toilet skills and to dress themselves. The DSM-5 (2013) refers to the practical domain whereby the individual with a moderate intellectual disability will be able to accomplish basic activities within the practical domain; however an extended period of teaching is needed, with a focus on basic personal care, which may include for example eating, dressing, elimination and hygiene. Whereas with individuals with a severe intellectual disability within the practical domain, support and supervision will be needed at all times with basic daily tasks, for example dressing, bathing and eating. It can be concluded that the more physical needs the sibling with an intellectual disability has, the greater the extent of support needed to perform certain tasks.

Sub-theme 2.2: The role of the parent(s) in the sibling's daily functioning

Participants seemed to struggle to indicate how their parent(s) support their sibling or their role in the daily functioning of the sibling. Nevertheless information gathered showed the type of support the siblings were in need of. The participants made the following statements:

"Sy help hom in baie goed." "...afvee storie tannie en om soos as hy bad dan help sy hom om in die bad te sit en as, ...en daar moet iemand as ons swem dan moet daar iemand by wees as hy soos gaan verdrink." / ["She helps in a lot of things…the wiping exercise and to assist him to sit in the bath and there must always be someone when we swim as he could drown."

''...Hulle is baie versorgend oor haar en hulle is altyd by haar." / ["...They are very caring of her and they are always with her."]

"Mother helps child to dress and to tie his shoes."

The excerpts clearly indicate that the participants acknowledge that their siblings are in need of assistance and supervision by their parent(s) in daily activities, like toilet training and dressing, as indicated by the DSM-5 (2013).

Sub-theme 2.3: The role of the adolescent in the sibling's daily functioning

The participants assist their siblings amongst others by looking after them, supervising them when they bath and to dress correctly. Participants expressed themselves in the following manner:

"...met die hemp om oor sy kop en om reg aan te trek."/ ["...to get his shirt over his head and to dress properly."]

"...Haar op te pas, partykeer uit te help en seker te maak sy't haar pille en my ma te help (met haar suster) as sy besig is..." / ["...To look after her, to help her sometimes and to make sure that she takes her pills and to help my mother (with her sister) when she is busy."]

"I can do a lot of things; I can care for him, like bath him, tie his shoes, I can brush his hair. When he is dirty I can clean him, I can do. When he ask me to give him water I do it, certain things like that I can."

As indicated in sub-themes 2.2 and 2.3, siblings with an intellectual disability experience complications with daily activities to such an extent that it reflects both the severity of their intellectual deficits and their adaptive functioning, as well as the

extent of assistance or support they demand (DSM-5, 2013). Govender (2002:2), as well as Kirst-Ashman and Zastrow (2007:125) add that having a child or sibling with a moderate to severe intellectual disability has unique influences on the nuclear family's functioning and may demand unique requirements of the parents and non-disabled siblings. Therefore the intensity of support and supervision that the sibling requires may have a negative influence on the family's functioning, based upon the family systems theory (Graff et al., 2008:240; Kirst-Ashman & Zastrow, 2007:138) This could imply a negative impact on relationships, which will be discussed in more detail in theme 3.

Sub-theme 2.4: Future support needed for the sibling with an intellectual disability

Participants struggled to explain whether their siblings would be in need of future support. Participants either did not know what to answer or according to them their siblings would be fine to live alone. Some participants stated the following:

"Sy sal basies alles self kan doen. Sy sukkel net om te skryf." / ["Basically she will do everything herself. She only struggles to write."]

"She will need to be encouraged to go to school ma'am and push hard so that one day she can be something she want."

"She will need someone who will look after her. Who will look after her children when she's at work?"

From the statements above, it is evident that some participants did not understand the reality of their siblings' abilities, the support needed and their inability to live alone. It is evident that these participants have a misconception of their siblings' functioning and abilities, including future support needed.

Other participants were able to acknowledge and express that their siblings will not be able to live alone in the future and will be in need of support. These participants had a better understanding of their siblings' functioning and expressed the following views:

''Iemand wat soos na hom kan kyk, want hy sal nie allenig kan wees nie." / ["Someone that can like look after him, because he will not be able to be alone."]

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''Nee ek glo nie sy sal alleen kan bly nie as gevolg van die epilepsie, want as sy die epileptiese "fits" kry dan moet daar iemand wees om haar te help, want sy kry glad nie suurstof nie'' / ["No I do not believe that she will be able to live alone, because of the epilepsy, as there has to be someone to help her when she gets the epileptic fits because she does not get oxygen."]

"Cannot live on his own, because he needs someone to help him.''

"Can work with hands but difficult to live alone."

''She needs someone to help her."

Some of the participants shared their future concerns regarding their siblings and acknowledged that they are unable to live on their own and need ongoing support in future, as described by the DSM-5 (2013). In theme 2 the unique challenges, current support and future support which siblings require, according to the participants, were outlined. In the following theme the focus will be on the relationships amongst the family members.

Theme 3: Relationships within the family

An individual with an intellectual disability may have a significant influence on other family members, including the nuclear family system as a whole (Moyson & Roeyers, 2012:88). Stoneman (2009:285) adds that the influence that the individual with an intellectual disability has on the family's functioning may be highly variable across families. In the following sub-themes the relationship within the family system and the unique influence that the sibling has on the nuclear family and their relationships will be described.

Sub-theme 3.1: The relationship between the sibling with an intellectual disability and the parent(s)

The participants could describe that there are positive aspects regarding the relationship between their sibling with and intellectual disability and their parent(s). Positive feelings that were specifically highlighted were love and joy. The participants expressed the following:

"Liefde vreugde en baie grappe....baie close." / ["Love, joy and a lot of jokes....very close."]

"...geduld...Soos liefde, ja tannie." / ["...Patience…Like love, yes ma'am."]

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"Love and Joy"

"Care and respect"

"Care, love, happiness and forgiveness."

"...The mother loves her. When the mother is there, there is love."

"Positive relationship…because he buy him anything he want."

According to the participants, the overruling emotions within the siblings' relationship with the parent(s) were love, joy and a feeling of caring for one another. They perceived this relationship as positive and lovable. In the second last quote the participant expressed the view that she experienced that her mother loves her sister, but that she was often not at home, which may be another challenge that the specific participant experiences within the home. Although the last statement by the participant was explained as a positive relationship it seemed as if the participant experienced resentment in that the parent bought the sibling anything he wanted and that this was the reason why their relationship was described as positive.

Participants also expressed the following negative aspects and emotions within the relationship between the siblings and their parent(s), according to their perception:

My pa word net geïrriteerd as sy hom die heeltyd vra om haar te help met die rekenaar. Dis basies die heeltyd....Partykeer dan huil sy, partykeer ignoreer sy net almal." [My father gets irritated when she asks him to help her with the computer, which is basically the whole time....Sometimes she cries, sometimes she just ignores everyone."]

"Yes my sister likes a lot of care of my mom ma'am, but it get so that my mom has to care for this little baby and sometimes Jacob (names provided are pseudonyms) need something to help her and it's impossible....Sometimes she hmm, she get anger, a lot of anger and then she don't want to speak to any people…effects their relationship, because sometimes she says words that she regrets ma'am…My dad's relationship with Jacob, not so close ma'am, because it's not my real father. It's good but they don't like chatting a lot to each other."

"He (mother) does shout at him. When he doesn't listen he scares him. He put the belt on the table and then Samuel start to listen."

"She's afraid of her, because every time she is talking to her, maybe for her to order, she is not talking properly like we are talking she is always loud shouting....Then the child is afraid because loud talking and shouting with a loud voice."

"Sometimes they don't get each other. John do some mistakes…Sadness…Anger…She (referring to John) will go out at night or going out without telling my mother where she is going....Just shout at her and tell her that she must not do this again, because she will get raped."

The above indicate that the participants felt that the main negative emotions that they could perceive in the relationship between their parent(s) and their sibling were anger, sadness and fear. The cause of conflict or stress was described as: anger due to outbursts by the parent(s) towards the sibling, which results in the sibling being fearful; anger or emotional outbursts by the sibling and then isolating themselves from the family; and lastly anger and concern experienced by the parent towards the sibling because of their misbehaviour.

The participants were able to empathise with their mothers and siblings. As described above, one of the participants explained that the situation at home is difficult for her mother, since she has to give attention and care to both her baby and to her child with an intellectual disability, which in affect angered the child (with the disability). Furthermore another participant shared that his sibling is afraid of his mother, as she is usually shouting and that his brother does not like loud shouting. According to Al-Krenawi, Graham and Gharaibeh (2011:147) parents of individuals with an intellectual disability may experience a high degree of stress and may find their circumstances economically, emotionally, psychologically and socially challenged. As a result tension can develop within the family and therefore between the siblings and their parents.

Sub-theme 3.2: The relationship between the participant and the sibling with an intellectual disability

Participants described their relationship with their sibling as positive. They explained that they liked playing with their sibling. Positive feelings that were expressed regarding their relationship with their sibling with an intellectual disability were mainly love and joy. The participants stated the following:

"'n Anderste tipe verhouding. Liefdevol ja, maar ook gevegte, maar soos in elke familie tussen broers en susters, maar wel daar vir mekaar." / ["A different type of relationship. Loveable yes, but fights as well, like in any family between brothers and sisters, but being there for each other."]

"We understand each other…we play together."

"...Always happy to be together..."

"...Care....happiness."

Participants could describe positive characteristics of their sibling and what they liked about their sibling. The participants had a positive attitude towards their sibling.

Participants could however also express negative aspects and emotions in their relationship with their sibling. The main negative emotions involved were feelings of irritation, frustration and anger.

Some participants shared their negative feelings towards their siblings as follows:

"Ek raak net party dae kwaad vir hom as hy my goed breek…Ek vloek my kussing…en ek gil in my kussing." / ["I just get angry when he breaks my stuff…I swear at my pillow…and I scream into my pillow."]

"Sometimes we get angry with each other, because sometimes we like shouting at each other because on weekends she like to watch television and I like to play, play station."

"...Maar ook gevegte, maar soos in elke familie tussen broers en susters…Partykeer irritasie, want sy't baie energie en ek't nie altyd so baie energie nie." / ["...But fights also, but like in any family between brothers and sisters…Sometimes irritation, because she has a lot of energy and I don't always have so much energy."

"Partykeer irriteer sy my, maar dis elke suster en broer." / ["Sometimes she irritates me, but that is every sister and brother."]

The above statements indicate that the participants were able to express the fact that their siblings sometimes made them angry; usually caused by frustration. Conflict was generalised and regarded in the same manner as in other "normal" sibling relationships. Feelings of irritation resulted from the sibling tiring the adolescent out because of her energetic nature.

Sub-theme 3.3: The influence of the sibling with an intellectual disability on the participant's relationship with his parent(s)

According to Mandleco et al. (2003:365), relatively limited research has explored the relationship between the parents' functioning and the non-disabled siblings' functioning when living in a family where a sibling has been diagnosed with intellectual disabilities. Participants found it difficult to explain how their siblings influence their relationship with their parent(s). Some of the participants were of the opinion that their siblings did not have any influence on their relationship with their parent(s).

Families with intellectual disabilities embrace unique benefits and these parents are able to rear their children within healthy and well-functioning families (Stoneman, 2009:256). The following positive influences were identified by the participants:

"Goed, ons spandeer baie tyd saam met mekaar. Partykeer gaan swem ons; partykeer gaan ons parkie toe." ["Good, we spend a lot of time together. Sometimes we go swimming; sometimes we go to the park."]

"Yes she is influencing my relationship with my mother to have love."

"We care for each other."

"...Hy sal soos partykeer as ons hartseer is dan maak hy partykeer dat ons lag." / [Sometimes he will make us laugh, for example when we are sad."]

The quotations above indicate that the participants experience that their siblings have a positive influence on their family and on their relationship with their parent(s). The participants voiced the fact that their siblings motivated them to spend more time together, to care for each other and to love one another.

However participants also stated that their siblings with an intellectual disability had negative influences on their relationships with their parent(s). Participants felt that their siblings received more attention and that they often felt left out. This evoked feelings of anger and/or sadness.

"...Daar is baie keer wat ek uit voel tussen haar en my ma." ["...There are often times when I feel left out between her and my mom."]

"Partykeer voel dit vir my of sy meer van hom hou as van my. ...ek is soos die verlore enetjie…Soos party dae vra ek haar om soos, as ons nou soos in êrens gaan ek wil haar dan net vra as ek soos 'n rukkie saam met my ma spandeer, dan moet hy altyd soos saam gaan. Hy wil nie dan by die huis, soos by my ouma bly nie." ["Sometimes I feel that she likes him more than me…I am then like the lost one....Like some days I would ask her whether I could spend time with her, but my brother always has to go along. He for instance never wants to stay at home with my grandmother."]

"My mother says he does mistakes so let's leave him, there is nothing we can do…I get upset. Because when I always do that my mother shouts at me."

The participants shared the view that they often felt left out, and that their siblings received more attention from their mothers, specifically. It is evident from these statements that they experience a desire to spend time alone with their mothers without their sibling being present.

Research done by Blacher and Baker (2007:333, 343, 344) indicates that behavioural problems that the individual with an intellectual disability display were directly correlated to negative experiences by the parents, specifically to parenting stress. Woolfolk and Perry (2012:621) add that if parent(s) experience extra stresses, this may as a consequence interfere with warm, involved parenting and with the non-disabled children's adjustment in any phase of development. Therefore, the participants could have experienced rejection and lack of attention due to their parents' stress and efforts involved in the care of their sibling with an intellectual disability. Consequently, based upon the family-systems theory, the relationship between the adolescent and his parent(s) can be negatively influenced as the sibling with an intellectual disability demands more attention and support from the parent(s), as indicated by the participants. In the following theme attention will be given to the influence that the sibling with an intellectual disability could have on the participant's functioning.

Theme 4: The influence of the sibling with an intellectual disability on the participant's functioning

The adolescent is in need of healthy support within the family system to help him during his unique process of change. Within families with intellectual disabilities, healthy functioning may be influenced or challenged (Graff et al., 2008:240).

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However, according to Begum and Blacher (2011:1581) research indicates that there seems to be inconsistent findings on the manner in which individuals with intellectual disabilities have an impact on their non-disabled siblings. In the following sub-themes the unique influences that the sibling has on the participant will be explored.

Sub-theme 4.1: The influence of living with a sibling with an intellectual disability on the emotional functioning of the participant

The participants expressed negative feelings in terms of their emotional functioning with regards to their sibling who has an intellectual disability. The participants expressed themselves in the following manner:

"Partykeer voel dit vir my of sy (my moeder) meer van hom hou as van my....ek is soos die verlore enetjie." / ["Sometimes I feel that she (my mother) likes him more than me… I am then like the lost one."]

"...Daar is baie keer wat ek uit voel tussen haar en my ma." / ["...There are often times when I feel left out between her and my mom."]

"Sometimes she doesn't want to listen. I don't know why. Maybe after school she comes and just throws her school bag aside…I feel like I did something bad to her, I feel guilty…because sometimes people will think that maybe there is something that we do to her or that we hurt her sometimes…I think that maybe she needs more support from my mother. I think so - that bothers me so much…it makes me stress a lot."

The above clearly indicate that the participants experienced that their siblings enjoyed preferential treatment from their parents, especially from their mothers. Feelings of worry, concern and stress were also shared regarding the wellbeing of the sibling. Berk (2012:638-639) and Papalia et al. (2006:461) are of the opinion that families with a child/sibling with intellectual disability experience unique demands and stressors which could negatively influence their functioning. Based upon the family-systems theory the child/sibling with an intellectual disability with his unique challenges and needs affect the rest of the family members, influencing the functioning of the family as a whole (Graff et al., 2008:240; Kirst-Ashman & Zastrow, 2007:138). Therefore, the support that the non-disabled adolescent requires in his process of developing a strong self-esteem could be impaired.

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Rathus (2006:554) explains that the development of a healthy self-esteem and self-worth plays a significant role during adolescence and tends to improve with emotional support from family and peers. Therefore, considering the participants' experiences, having a sibling with an intellectual disability may demand extra individual attention from the parent(s) which could negatively affect the support or attention that the participants desire.

It seemed that the participants struggled to describe the positive influences that their siblings had on them – in terms of their emotional functioning. Some participants could however state that their sibling had a positive influence on them in the following manner:

"I can say, I feel proud for him and I feel happiness and he is a good brother for me."

"Sy het baie my lewe beïnvloed, want soos as sy nie daar was nie, ek sou ook soos ander mense gewees het; as ek soos sulke kinders gesien het en geoordeel het voordat ek geweet het. Maar nou…sy't (my suster) dit so beïnvloed op daai manier dat ek opkom vir daai mense." / ["She has influenced my life a lot, because if she was not there I would also be like other people; I would have judged children like that, before I knew. However, now she (my sister) has influenced it in such a manner that I stand up for those people."]

The statements above indicate that the participants were able to express the view that their siblings had influenced their lives positively. The participants shared deep appreciation for their siblings. These statements affirm the opinion of Graff et al. (2008:239) and Benderix and Sivberg (2007:400, 401) in that the sibling with an intellectual disability may contribute to the non-disabled child's development of empathy, responsibility and other positive strengths in due time. Blacher and Baker (2007:331) add that children with a sibling with an intellectual disability develop increased sensitivity and tolerance, improved family dynamics and hence a changed perspective on life.

Sub-theme 4.2: The influence of living with a sibling with an intellectual disability on the school related performance of the participant

During this research the participants voiced the view that their siblings had a negative influence on their concentration at school and influenced their school work. Some participants expressed themselves in the following manner:

"Sometimes eish when I do my schoolwork I just think about her." "...I think that maybe she needs more support from my mother, I think so. "...That bothers me so much." "...It makes me stress a lot."

"Sometimes it is difficult when I need to concentrate on my school work when I'm thinking about her (sibling's) disability and at some point it affect my schoolwork or it affect her at school."

"When I tell him that I'm now going to do homework he does let me, but then after two minutes he goes and makes some noise. After making some noise I can't concentrate. I have to close my books and let him go and I can concentrate."

The views voiced above show that the participants struggled to concentrate on their school work because of their sibling with an intellectual disability. The reason why the participants' got distracted and struggled to concentrate was because of feelings of worry and stress, and concern about their sibling. Research done by Begum and Blacher (2011:1581) confirm these sentiments which indicates that siblings with an intellectual disability have a negative influence on their non-disabled adolescent siblings in that they experienced internalising behavioural problems and academic problems.

Sub-theme 4.3: Influence of living with a sibling with an intellectual disability on the social life and friendships of the participant

Some of the participants felt that their sibling with an intellectual disability had no negative influence on their friendships and that their friends regarded their sibling in a positive manner. The following statements are a testament to this:

"...Hy beïnvloed dit nie. Hy speel eintlik met almal, want al my vriende weet hoe's Markus en hulle speel nogals lekker saam."

"They see her fine, they see her fine. They don't know that she is slow."

"They understand that madam, she is…not good at school, but she loves people so they understand and they respect her too."

"She does not influence my relationship with my friends. They have just accepted her and are okay with her."

The above quotations show that it is clearly evident that these participants experienced that their friends regarded their siblings in a positive manner and that they accepted them. The participants did not share any negative feelings regarding their sibling having a negative effect on their friendships. However, negative experiences were expressed by some participants regarding their friends not treating their siblings appropriately. The participants stated the following:

Hulle sien haar as anders, hoe kan ek sê, as snaaks, 'n grap....Ek het dit al beleef, so…soos hulle "try" haar wegstoot soos die heeltyd. Maar dit gaan nooit werk nie en dan los ek daai vriend. Maar jy kry daai vriende wat haar insluit…Dit het my al beïnvloed deur te sien hoe die mense rerig is of vir wat hulle voorgee hulle is." / ["They see her as being different, what can I say, as being funny, a joke....I've experienced it like that…They for example try to push her away, the whole time. But it will never work and I then leave that friend. However you have those friends that will include her…It has influenced me to see how people really are or who they pretend to be."]

"Some of them throws at him with rocks and things and some of them swear at him and he gets very angry …I get angry and I tell them that Jacob is too old …they swear at him and throw him with rocks."

"I tell them he is not crazy....Then I don't play with them for a few times."

The above quotes indicate that some participants have had negative experiences with friends acting in a negative manner towards their siblings, referring to name-calling, swearing and harassing them by throwing them with rocks. These experiences indicate that the participants' sibling sometimes had a negative impact on their social life and friendships (Begum & Blacher, 2011:1581). During adolescence, social acceptance is important and peer influence is usually a prevailing psychosocial issue (Stang & Story, 2005:6). However, the findings above indicate that it is evident that the participants were more concerned about their siblings than about their friends who treat their siblings poorly. Participants reported that they would protect their siblings against name-calling. One participant shared that she developed insight about the nature of true friends.

During the discussion of theme four it became clear that the siblings could have both a positive and negative influence on the participants' functioning. In theme five the need for support systems will be discussed.

Theme 5: The need for support systems

Families raising children with intellectual disabilities tend to face challenges above and beyond those faced by "typically" developing children. These challenges may be caused by factors ranging from increased problem behaviours shown by children with intellectual disabilities, to greater exposure to poverty, stigma, and social exclusion. For many families, and especially for families in low- and middle income countries, these challenges will be intensified by the absence of sufficient and proper services and supports (Families Interest Research Group of IASSIDD, 2014:425). According to Adnams (2010:439) there appears to be marked inequities in human rights and access to care and services for a large number of individuals with intellectual disabilities in South Africa. The lack of sufficient services for individuals with intellectual disabilities may set great challenges for these individuals, including the family members involved. In the following sub-themes the need for different support systems for families with an individual with an intellectual disability are presented.

Sub-theme 5.1: The need for support groups for the participant / for family members

The participants were of the opinion that there is a need for support groups for families with intellectual disabilities. The following expressions were forwarded by the participants:

"Ek dink so tannie…Soos as daar soos twee gesinne is soos Markus, soos hulle kan met mekaar praat soos by die skool want hy sien eintlik uit om skool toe te gaan soos ek eintlik uitsien om nie skool toe te gaan nie." ["I think so ma'am...Like when there are two families like Markus (his sibling with an intellectual disability) like they can talk to one another, because he actually looks forward to going to school, like I do not actually look forward to going to school."]

"Ek dink hulle waardeer baie daai ondersteuning, want hulle kort soveel soos wat hulle kan kry, want dit is moeilik met so 'n persoon." / ["I think they appreciate that support, because they need as much support as possible as it is difficult with such a person."]

"Because madam when we can help each other we can help when we don't know, like sometimes we learn things from each other."

"Yes…Because some children that go to Boiteko they don't want to go to Boiteko because they think when they go to school they will all be laughed at."

Statements from the participants reveal that support groups would be helpful. Participants motivated that it is challenging to live with an individual with intellectual disabilities and the stigma around the centres for people with intellectual disabilities influence their siblings negatively. Information obtained is substantiated by Bennet and De Luca (in Edwardraj et al., 2010:746) who state that assistance from support groups may be of benefit to parents and non-disabled siblings in managing the offloading of negative feelings and emotions, and sharing common experiences. Furthermore, support groups can also assist in obtaining specific information about care and treatment, according to Edwardraj et al. (2010:746).

Sub-theme 5.2: The need for professional counselling for the participant / family members

The participants voiced the opinion that their family would benefit from counselling services to talk about their negative feelings. The participants stated the following:

"Om ons emosies en alles wat ons nie like uit te spreek, ja." / ["To speak about our emotions and everything that we do not like, yes."]

"I think maybe Grace (sibling with an intellectual disability) can stop being emotional so much."

"Ja ek dink dit sal ook kan help, want almal "try" voorgee dit gaan goed en daar is niks fout nie, maar daar is fout dan." / [Yes I think it could help as well, because everyone tries to pretend that they are fine and that nothing is wrong. However, there is something wrong.

Statements from the participants reveal the need for professional counseling services, thus emotional support for them and their family members. The participants were of the opinion that counseling could help them and their family members to manage their negative emotions better.

Sub-theme 5.3: The need for educational programmes on intellectual disabilities

As a result of a lack of knowledge and understanding about intellectual disability as a phenomenon, the participants shared the need to be better educated regarding

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intellectual disabilities. The participants expressed themselves in the following manner:

"Ja tannie dit kan ook nogals 'n bietjie help tannie, as jy weet wat kan jy met hom kommunikeer en hoe kan jy met hom speel". / ["Yes it will help somewhat ma'am, if you know how to communicate and how you can play with him."]

"Dit help, want my ma was al by so iets." "...Nou verstaan sy beter wat is dit en hoe dit eintlik moet gaan…Om beter te verstaan waar kom dit vandaan en hoe het dit begin." / ["It helps, because my mom has been to something like that…Now she has a better understanding about how things should work…In order to understand where it comes from and how it originated."]

From the above statements it is evident that the participants are of the opinion that they could benefit from educational programmes on intellectual disabilities. Only one participant stated that her mother had attended an educational session regarding intellectual disability and that she benefitted from it. However, the rest of the participants were unaware of any educational programmes for families with intellectual disabilities. Furthermore, public awareness, education and community-level intervention are necessary for reducing misconceptions and stigma related to intellectual disability in order to improve the attitudes towards and management of intellectual disabilities (Edwardraj et al., 2010:736).

Sub-theme 5.4: The need for additional coping strategies

According to Graff et al. (2008:240) members of the family system are interdependent in order to function effectively. Based upon the family-system theory a sibling with an intellectual disability can have a unique influence on the family's functioning and coping mechanisms. The participants shared the need to learn better coping strategies for them and their family members. The following excerpts are a testament to this:

"Ja tannie, want tannie gewoonlik as hy baie kwaad word dan byt hy homself." ["Yes ma'am, because ma'am usually, when he gets very angry he bites himself."]

"Ja dit sal help want dan kan mens ook beter verstaan hoe om stres te hanteer en hoe om spesifiek daarmee saam te leef." ["Yes it would help, because then you can better understand how to handle stress and how to specifically live with it."]

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From the above it is clear that the participants voiced the need for guidance and are requiring more effective coping mechanisms for themselves and their family members. The participants were of the opinion that poor management of anger and fear was evident in their family and that they had a need for improved coping skills in their families. These findings relate to that of Wang, Michaels and Day (2011:784) who support the negative correlation that exists between stress in families with children with intellectual disabilities and their social supports and coping skills. Therefore, if better coping strategies of family members, within their unique situation of living with a sibling or child with an intellectual disability can be developed, the family's functioning can be improved.

3.9   SUMMARY

This chapter outlined the research methodology used during the study, research findings as well as an analysis and interpretation of the responses of the non-disabled adolescents.

In the following chapter, conclusions and recommendations regarding the findings of the research will be presented. These recommendations will focus on practitioners of developmental social work who are positioned to implement programmes and support services for adolescents living with a sibling with intellectual disabilities and their family members.

CHAPTER 4

CONCLUSIONS AND RECOMMENDATIONS

4.1. INTRODUCTION

When initiating the research, the researcher set a specific goal and objectives to be achieved. In this chapter the focus will be to examine the extent to which the goal and objectives have been met. Conducting a study on the experiences of adolescents living with a sibling with a moderate to severe intellectual disability demanded reviewing literature and analysing empirical findings. The key outcomes of the empirical study and the literature review will be outlined in order to provide conclusions and recommendations. Lastly, in this chapter the researcher will comment on the opportunities for future research, based on the findings of this study.

4.2. ACCOMPLISHMENT OF THE RESEARCH GOAL AND OBJECTIVES

The research goal and objectives set the criteria for the researcher to determine whether the research endeavour was successful and whether the goal of the research has been reached. In this section the extent to which the goal and objectives were achieved and the manner in which this has been accomplished, will be discussed. Lastly, recommendations will follow, including guidelines for professionals working with families with a child/sibling with intellectual disabilities with the main focus on the non-disabled adolescent.

4.2.1. Goal of the study

The **goal** of the research was to explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability. The attainment of the research goal was made possible by focusing on the objectives formulated for this study. These objectives are outlined and a discussion of how the objectives were achieved will follow.

The **research objectives** of the study were as follows:

Objective 1: To contextualise moderate to severe intellectual disability, as well as adolescence as a life stage.

This objective was achieved in Chapter 2 where intellectual disability was defined as a developmental intellectual disorder and the all-encompassing diagnosis and criteria for each level of intellectual disability, referring to adaptive and intellectual functioning and the onset of deficits during the developmental period were outlined. Furthermore, adolescence and the developmental characteristics were discussed and contextualised as a life stage, as well as a variety of changes and challenges occur during adolescence. These changes and challenges require certain adjustments and mastery of developmental tasks that can be uniquely affected within a family that has an individual with an intellectual disability.

Objective 2: To explore the experiences of adolescents living with a sibling with a moderate to severe intellectual disability in terms of their emotions; their relationships with their sibling and with their parents; as well as the influence of living with their sibling on their lives.

The research findings and interpretations in Chapter 3 (See Section B: Research findings and interpretations) report on the participants' experiences of living with their siblings with an intellectual disability. The qualitative findings were interpreted from the family-systems theory.

The participants expressed their experiences and emotions on how the public regard their siblings with an intellectual disability positively (see Chapter 3, sub-theme 1.2: *The public perceive their siblings in a positive manner only*), as well as negatively (see Chapter 3, sub-theme 1.2: *Individuals from the general public stereotype intellectual disability and tease their siblings, by making use of name calling).* The adolescents described the relationships within their family and the unique influence of their sibling on those relationships (see Chapter 3, sub-theme 3). Participants found it difficult to respond to how their sibling influences their relationship with their parent(s). Adolescents could identify positive influences that their siblings had on their relationship with their parents as they motivated love and caring within the family. However, negative experiences were shared that evoked feelings of anger

and sadness because they felt that their siblings received more attention and that they often felt left out (see Chapter 3, sub-theme 3.3)

As a result, these questions evoked other unique emotions within the participants on how their siblings influenced their lives, specifically their emotional and social functioning (see Chapter 3, sub-theme 4.1).

Objective 3: To make recommendations for practitioners and to create awareness about the experiences of adolescents living with a sibling with a moderate to severe intellectual disability.

The family-systems theory places emphasis on the interconnectedness of family members and that the development and behaviour of one family member is indefinitely interconnected with others in the family. With this in mind, information obtained from the participants, regarding their experiences of living with a sibling with an intellectual disability, creates awareness of the need for specific support for such adolescents and their families in order to improve their functioning as a whole (see Chapter 3, sub-theme 5).

Chapter 4 (paragraph 4.4.1) outlines the practical guidelines for practitioners working with families with an individual with intellectual disabilities on areas where lack of support exists, how to counter certain challenges and build on the possible existing strengths of these families.

The goal and the objectives were therefore achieved as discussed above. In pursuing these objectives and the overall goal, the researcher highlighted key findings from the research. In the following section, these key findings will be discussed.

4.3   KEY FINDINGS

The **research question** was as follows: "What are the experiences of adolescents living with a sibling with moderate to severe intellectual disability?" It can be reported that this research question was answered during the research process, where the experiences of adolescents living with a sibling with a moderate to severe intellectual disability have been identified and presented in Chapter 3 of this study. The answers

to the research question and by implication the **key findings** of this study will be discussed in the following section.

Participants living with a sibling with a moderate to severe intellectual disability experienced the following:

- Participants were unfamiliar with the term intellectual disability and struggled to describe this concept.

- It seemed as if the lower the socio-economic background of the participant, the less likely he was to have basic knowledge and insight into his sibling's condition and the implications thereof.

- Some participants perceived the reaction of the public towards their siblings and persons with intellectual disabilities as negative. Adolescents voiced feelings of anger towards the labelling and name calling by the public.

- The participants perceived the relationships between their siblings and their parents as both positive and negative. Feelings experienced were portrayed as love and joy, as well as anger, sadness and fear.

- Some participants felt left out or not good enough because of their siblings receiving more attention or preferential treatment from their parents. As a result emotions of sadness and anger were experienced.

- Some participants were concerned about their siblings' care and support. They experienced worry, stress and guilt regarding their siblings in terms of care and support. As a result, their schoolwork was influenced negatively.

- The siblings with an intellectual disability influenced the participants' lives positively as well. The development of greater understanding for individuals with intellectual disabilities was enhanced.

- The majority of participants were in favour of support and educational groups, professional counselling, as well as guidance in terms of coping mechanisms.

From the key findings the researcher could derive conclusions regarding the experiences of adolescents living with a sibling with a moderate to severe intellectual disability. These conclusions will be presented in the next section.

4.4. CONCLUSIONS

The literature review enabled the researcher to gain valuable information regarding families with an individual with intellectual disabilities. The literature could support some of the findings reached in the empirical study. Subsequently conclusions are presented, based on both the literature review and the empirical study.

4.4.1. Literature review

The conclusions construed from the literature review are outlined in the following manner:

- The extent to which the parents of children with an intellectual disability are educated regarding their child's condition seems to be affected by poverty, lack of services and lack of education.

- Research data on the causes of intellectual disability in South Africa is limited and unreliable. A primary cause of intellectual disabilities can be identified in only approximately 25% of those affected.

- Families raising children with intellectual disabilities tend to face challenges above and beyond those faced by non-disabled children. Family members, failing to meet their role requirements may cause breakdowns in family functioning that may increase distress and impair healthy psychosocial functioning in the family.

- The influence that the individual with an intellectual disability has on the family's functioning may be highly variable across families. Such families may develop unique strengths that can add a positive dynamic to the family's functioning.

- The person with an intellectual disability experiences complications with daily activities to an extent that reflects both the severity of his intellectual deficits and his adaptive functioning, as well as the extent of assistance or support he requires.

- Non-disabled children's experiences will vary in accordance with their developmental stage and the severity of the intellectual disability of their sibling. The family's challenges may relate to factors ranging from the rates of

increased problem behaviours shown by their siblings with intellectual disabilities to increased exposure to poverty, stigma, and social exclusion.

- Living with a sibling with an intellectual disability can result in having multiple negative influences on the adolescent's life, such as emotional and internalising behavioural problems, social challenges and academic problems.

- The development of a healthy self-esteem, self-worth and role identity play a significant role during adolescence and tends to improve with emotional support from family and peers. Parents within families with intellectual disability might struggle to support and to be involved in the lives of their non-disabled children, because of the unique challenges and stresses that they experience. Therefore, the adolescent might face challenges in developing a healthy role identity.

- According to research, the non-disabled sibling experiences stress in coping with public reactions and discrimination towards their sibling with an intellectual disability.

- Researchers indicate that the positive influences of having a sibling with an intellectual disability on the parents and siblings are often overlooked, thus undermining the potential of strengths that such families may have and are able to develop.

- The sibling with an intellectual disability could contribute to the non-disabled adolescent's development in terms of positive life experiences and maturing in strengths, for example empathy and responsibility. However, because of the adolescent's lack of knowledge and support he might not realise the potential strengths unique to his situation.

- For many families with a child or sibling with an intellectual disability, and especially for families in low- and middle income communities, challenges faced will be intensified by the absence of sufficient and appropriate services and support systems.

- In South-Africa there are service gaps, especially for adolescents and adults with intellectual disabilities. This gap is clear from literature that has been published on services for individuals with intellectual disabilities. The lack of sufficient services leads to challenges for these individuals and their families.

- Children living with a sibling with intellectual disabilities may benefit from individual or individual sibling pair intervention or support groups. Parents and non-disabled siblings can benefit from support groups, especially in managing the offloading of negative feelings/emotions and in sharing common experiences.

- Furthermore public awareness, education and community-level intervention are necessary for reducing misconceptions and stigma related to intellectual disability in order to improve the attitudes of the general public as well as the management of intellectual disabilities.

4.4.2 Empirical findings

Conclusions based on empirical findings are presented in the following section:

- Participants were unfamiliar with the term intellectual disability and they demonstrated a limited ability to define intellectual disability intellectual as a phenomenon. As a result they had a lack of knowledge regarding their siblings' functioning; necessary current and future support needed.

- The participants could recognise some symptoms of intellectual disability in their siblings, as described in the DSM-5 (2013). Therefore, they had the ability to notice typical characteristics and challenges of persons with intellectual disabilities.

- Poverty can hinder one's access to services and education on intellectual disability. Therefore, the participants from a lower socio-economic background indicated a lack of basic knowledge on intellectual disability as phenomenon, as well as limited insight regarding their siblings' condition and the implications thereof.

- The general public acts negatively towards the participants' siblings by name-calling and labelling. The publics' reactions have made participants angry and upset, as they found such behaviour unacceptable.

- Depending on the siblings' special needs, the participants supported them. Some siblings were in need of support in reading and writing (intellectual challenge) and in dressing (physical challenge). The greater the severity of the intellectual disability, the greater the need for support.

- The participants had a generally positive attitude towards their siblings. They appreciated their siblings, despite negative feelings that were occasionally experienced.

- The siblings have a positive influence on the participants' relationships with their parents as they prompted a general feeling of love and care for each other in their families.

- The siblings required additional assistance and supervision from their parents and enjoyed preferential treatment and attention. As a result, feelings of sadness and anger were experienced by the participants. The development of a healthy self-worth is especially important during adolescence. Therefore, the adolescent might face challenges in developing a healthy self-esteem and role identity if feelings of rejection and lack of support persist.

- Some participants were concerned about their siblings' future care and support. They were emotionally affected by this as they experienced stress and guilt regarding their siblings' wellbeing. As a result, it sometimes influences their ability to concentrate at school, which influences their performance in academic work.

- The sibling with an intellectual disability may contribute to the participant's development of positive life experiences and maturing in strengths, for example the development of empathy and a deeper understanding for individuals with intellectual disabilities.

- Although living with a sibling with an intellectual disability may contribute to positive life experiences and learning, the participants could be unaware of this, because of their lack of insight and understanding and due to a lack of support from their parents and the community.

- Siblings had a positive influence on the participants' social functioning. Their friends accepted their siblings and treated them well. However, some participants had negative experiences in this regard. Some participants' friends mistreated their siblings by means of name-calling, swearing and harassing them. These participants stood up for their siblings and came to their defence.

- The participants were in favour of professional counselling services for themselves and their families. They were in need of emotional support, for

themselves and their family members. Participants were of the opinion that their families would benefit from guidance in learning healthier coping mechanisms, as anger and fear persisted amongst their family members. Furthermore, the participants were of the view that counselling could empower them to manage and express their negative emotions.

• The participants were of the opinion that families with a child/sibling with intellectual disabilities would benefit from support groups. It is challenging to live with an individual with intellectual disabilities and the limited understanding of intellectual disability and stigma around people with intellectual disabilities by the public, influence their siblings negatively. Therefore, the majority of participants were in favour of support groups.

• As a result of a lack of knowledge and understanding regarding intellectual disability as a phenomenon, the participants shared the need to be better educated in terms of intellectual disabilities. Participants were also unaware of any educational programmes for families with a child/sibling with intellectual disabilities. They were in favour of participating in educational groups to be better informed on intellectual disability as a phenomenon.

By means of the key findings and conclusions formulated from the research findings, the researcher is able to make recommendations for practitioners, as well as in terms of future research.

4.5 RECOMMENDATIONS

Recommendations are presented in two subsections. Firstly, recommendations for practitioners working with families with an individual with intellectual disabilities will be provided. Secondly, recommendations for future research will be proposed.

4.5.1 Recommendations for practitioners

The following recommendations are proposed for practitioners working with families with an individual with moderate to severe intellectual disabilities.

• Considering that inadequate knowledge and information on intellectual disability exist amongst families with an individual with intellectual disabilities, attention has to be given to educating these parents and family members regarding intellectual disability as phenomenon. As a result misconceptions,

unrealistic expectations and family conflict, that surface due to a lack of knowledge might be eliminated. Furthermore, parents could be enabled to recognise existing support services in their surrounding communities that they could benefit from.

- Considering the need for support services identified through this research, practitioners should ensure the rendering of therapeutic services, as well as support and educational groups. These support services could provide relevant information and teach adequate coping strategies to families with an individual with an intellectual disability. In rendering these services practitioners can play a role in reinforcing such families' wellbeing, socio-emotional functioning and interpersonal relationships.

- Research also indicated that the general public seems to have a lack of knowledge regarding intellectual disability as phenomenon. Practitioners working with families with an individual with an intellectual disability can implement community awareness projects in cooperation with the existing centres for people with intellectual disability in order to empower the community with adequate knowledge regarding intellectual disability. As a result stigma, discrimination and bullying associated with intellectual disability could be reduced.

4.5.2 Recommendations for future research

The researcher recommends the following in terms of future research:

- It appeared that parents were either uneducated regarding the diagnosis and severity of intellectual disability of their child or did not communicate this information adequately to their non-disabled adolescent. Therefore, further research can focus on the parents, specifically regarding their experiences, challenges and the support needed in living with a child with an intellectual disability within a South African context.

- Seeing that this study focused on a small sample of families with moderate to severe intellectual disabilities within the Carletonville area in South Africa, which included Afrikaans, English, Xhosa and Setswana speaking participants only, it is recommended that a future study be conducted, focusing on a broader target group.

- The researcher believes that it will be valuable to explore and describe a cross-section of perceptions regarding intellectual disabilities as phenomenon.

- It would be significant to explore cultural and religious beliefs regarding intellectual disability as these beliefs have an influence on an individual's experiences, perceptions and attitudes.

- Intellectual disability and the different levels of severity imply unique challenges for the individual with the intellectual disability and the family members involved. Due to the fact that families with a child or sibling with profound intellectual disabilities were not included in this study, it is suggested that research be conducted specifically with these families.

4.6   CONCLUDING REMARKS

"Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid." – Albert Einstein

The individual, with or without an intellectual disability, is unique and filled with potential, strength and capacity. Therefore, we are obligated to recognise and motivate each one's ability and the value that a specific individual could bring to his family, community and society.

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