EXPLORING THE EXPERIENCES OF THE SIBLING OF A CHILD WITH AN INTELLECTUAL DISABILITY

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature: ....

Date: .....28 February 2008.........

SUMMARY

This study is aimed at gaining insight into the experiences of siblings of an individual with an intellectual and physical disability. Attaining greater insight into their lived reality, their feelings and concerns could make it possible to provide appropriate support.

The review of selected literature provides information on many aspects of the these siblings' experience. Although many studies are quantitative in their approach, the literature review provides relevant and useful findings and inferences which were used to support and substantiate findings. During this qualitative study, which is situated within an interpretive phenomenological paradigm, four participants between the ages of eight and sixteen years were interviewed using semi-structured interviews. This format of interview allowed participants to use their own words to express their personal experiences.

The results showed that siblings have both positive and negative experiences when another sibling has an intellectual disability. Other common difficulties include embarrassment, guilt, and the experience of differential treatment. Positive experiences and competencies include love and acceptance, personal growth, maturity, pride in siblings accomplishments, and appreciation for one's sibling. Several experiences were congruent with those mentioned in the literature.

The insights into the experiences this study provides has implications for the development and provision of sibling support programmes and interventions. At present, state group support programmes for siblings are not provided within the Western Cape area. The interventions and assistance that do exist seem to be provided by the private sector only. Support can prove very costly, which means that it is not accessible to many who require it. Sibling workshop groups could provide a valuable support alternative to a currently "unsupported" group, the siblings.

OPSOMMING

Hierdie studie poog om insig te verkry in die ondervindings van die broers en susters van 'n kind met intellektuele en fisiese gestremdhede. Beter insig in die realiteit van hul leefwyse, hulle gevoelens en bekommernisse kan beter ondersteuning aan hulle moontlik te maak.

Die ondersoek van geselekteerde literatuur voorsien inligting rakende vele aspekte van die ondervindings van hierdie kinders. Alhoewel baie van die studies kwantitatief in hul benadering is, het die bestaande literatuur tog relevante en bruikbare bydraes en gevolgtrekkings verskaf wat gebruik kon word om bevindings te bevestig en te staaf. Hierdie kwantitatiewe studie het plaasgevind in 'n verklarende fenomenologiese paradigma en vier semi-gestruktureerde onderhoude is gevoer met deelnemers tussen die ouderomme van 8 jaar en 16 jaar. Hierdie formaat van onderhoudvoering dra by dat deelnemers hulle gevoelens in hul eie woorde uitdruk.

Die bevindings het gewys dat broers/susters beide positiewe en negatiewe ondervindings van kinders met 'n intellektuele gestremdheid het. Ander algemene probleme sluit in skaamte, skuldgevoelens en die gevoel van gedifferensieerde behandeling. Positiewe ondervindings en vaardighede van broers en susters sluit liefde en aanvaarding, persoonlike groei, volwassenheid, trots op die broers/suster se bekwaamheid en die waardering van so 'n broer/suster in. Verskeie van die ondervindings het ooreengestem met bevindings wat in die literatuur gevind is.

Die insigte in hierdie ondervindings wat deur hierdie studie voorsien word het implikasies vir programme en intervensies wat ondersteuning aan hierdie kinders bied. Tans is daar nie sodanige staatsgefinansierde ondersteuningsprogramme in die Wes-Kaap area nie. Die intervensies en ondersteuning wat wel beskikbaar is word slegs in die privaatsektor aangebied. Ondersteuning kan baie duur wees, wat beteken dat dit vir baie kinders wat dit nodig het, ontoeganklik is. Ondersteuningsgroepwerkswinkels kan 'n waardevolle alternatief bied vir die "nie-ondersteunde" groep, die kinders.

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CHAPTER 1

INTRODUCTION TO THE STUDY

"For every bit that I have helped her,

she has helped me just as much, if not more.

She has shaped who I am

and taught me the most basic values

that are often overlooked in our fast paced society.

She has taught me to never give up,

to be grateful for everything I am, everything I have,

and to always love, laugh and play"

(Wilson, 2004:90)

1.1   INTRODUCTION

Meyer (1993:1) sees the sibling relationship as likely to be the most enduring family relationship in any family. Siblings usually have many more years of contact and involvement with each other than with parents or caregivers. This directly affects the life experiences of the sibling of a child with a disability. At present, however, as Gorelick (1996:6) points out, the needs of these siblings are neglected in the sense that they are not "directly consider[ed]" by support services, which focus primarily on the needs of the child with a disability and their parents. Dia and Harrington (2006:187) arrive at a similar conclusion. Although there has been considerable research on the topic of disability and the effects it can have, there is relatively little research on the siblings of a child with a disability, their experiences and feelings.

A number of studies have been done on disability in the family. Particular studies have looked at:

- parental stress levels when a child has a disability (Lessenberry & Rehfeldt, 2004);

- the parent-child interaction when a child has Down syndrome (McCollum & Chen, 2003);

- pre-school children with intellectual disability and maternal well being (Eisenhower, Baker & Blacher, 2005);

- mother's expressed emotion towards children with and without intellectual disabilities (Beck, Daley, Hastings & Stevenson, 2004);

- the mother's awareness and sibling adjustment (Taylor, Fuggle & Charman, 2001);

- the effects of disability on the family experience (Marsh & Johnson, 1997);

- the familial effects of disability on family system functioning (Dyson, 1996);

- the differential treatment of siblings in a family (McHale & Pawletko, 1992; Daniels & Plomin, 1985);

- communication behaviours in the siblings of children with autism (Goldberg, Jarvis, Osann, Laulhere, Straub, Thomas, Filipek & Spence, 2005), and

- sibling interactions (Caro & Derevensky, 1997).

It seems that there is a good deal of research on various aspects of disability. However, there is a clear need for further research to enhance and add to the information that has been obtained thus far. One area that requires more research is siblings of a child with a disability.

This study on the lived experiences of a child with a disability falls within a larger project entitled 'Quality Lifespan Development'. This study which was initiated in 2001 is situated in the Department of Educational Psychology at Stellenbosch University (SU). My involvement in aspects of this project, as well as associated studies, aroused my interest in what specific effects there would be on siblings who have a brother or sister with a disability.

1.2   AIM OF THE STUDY

As Durrheim and Wassenaar (1999:54) argue, a research study aims to provide specific information on the central area of investigation of the study. The aim of this study was twofold. The primary aim was to increase our understanding of what these siblings experience in their daily lives as a consequence of having a brother or sister with a disability. This involved exploring and documenting the experiences of siblings

who have a brother or sister with a disability. This study hoped to confirm or refute the findings of previous studies and to gain greater insight into the needs of siblings. The second aim was to provide information that would help to define the express needs of these siblings. The insight gained into siblings' experiences could prove useful in future studies regarding the development and/or implementation of effective interventions or support services that are practicable, accessible and affordable.

I feel it important to note that during this study I did a very thorough search to identify support organisations, interventions or programmes for the siblings of a child with a disability in the Western Cape. I was unable to locate any support group programmes that these siblings, and consequently their families, could benefit from. Only costly private support or interventions, which are not a viable option for the majority of families in South Africa, were available. While this study explores the experiences of four particular siblings, the findings could be used to gain a greater understanding of siblings of a child with a disability in general.

1.3   PROBLEM STATEMENT AND THE BACKGROUND TO THE STUDY

My interest in this topic stems primarily from my role as an Educational Psychologist. During my internship as part of the Master's programme, considerable attention was given to the topic of learners with impairments and the inclusive education system now being implemented in the South African education system. During this time I realised that many of the functions and roles of the Educational Psychologist are directly related to the child experiencing a difficulty. Whilst researching the implementation of Inclusive Education in South African schools, I came across, albeit fleetingly, the story of the sibling of a learner with a disability. I was struck by the reported additional strain on her when her sibling joined the mainstream high school that she attended. She was initially required to assist him during lessons and was thus responsible for meeting some of her brother's needs as well as her own. This led me to wonder about her daily experience of assisting her sibling, and the associated emotional and psychological effects this had on her. Since this sibling was obviously influenced by her brother's disability in the school system, it raised an important question that I wanted to explore: How do siblings experience their brother or sister's disability in their daily life?

I hoped that this study would make it possible to provide effective support and specific guidance for these siblings. Through hearing the concerns they have about their siblings, families and themselves, as well as the stories of these children who are able to 'cope' with less attention, relative to the siblings with a disability, we can start to provide information about their unique, and perhaps overlooked, needs. Various studies suggest that the siblings of a child with a disability experience a range of emotions and behaviours, from constructive experiences to difficult issues and problems (Burke, 2004; Caro & Derevensky, 1997; Ligthart, 2002; McHale & Gamble, 1987; Meyer, 1993; Meyer & Vadasy, 1996; Opperman & Alant, 2003; Pit-Ten Cate & Loots, 2000; Ross & Cuskelly, 2006; Russel, Russel & Russel, 2003; Strohm 2001). The majority of studies, some of which are mentioned above, used quantitative measures to present findings on expressed emotions, reported behaviours, observed interactions etc. Quantitative information is useful in determining statistical significance of data regarding predetermined categories (Durrheim, 1999:42), but it offers only very limited insight. I hoped that this qualitative study would raise awareness of the siblings' experiences and that the description of their personal experiences would make deeper insight possible. Bless and Higson-Smith (1995:100) noted that the type of data gained from a study determines the way in which it can be used. Thus in order to provide effective support for these siblings, we first need to develop a profound and realistic understanding of their lived experiences as described in their words.

Considering the limited qualitative findings on the actual lived experiences of these siblings, the research question in this study was formulated as: "What are the experiences of a sibling when a child in their family has an intellectual disability?" As noted by Durrheim (1999:40) exploratory research is adaptable in the course of enquiry and assumes an inductive approach. This study aimed to access and gain insight into the experiences of a children whose own stories may at times become "virtually invisible" amongst the vast scope of research, literature, support and information provided for their siblings (Gorelick, 1996:3).

As discussed above, studies relevant to this topic appeared largely quantitative and lack the depth of qualitative exploration of personal accounts makes possible. However, despite the limited amount of qualitative data, the findings of studies are

able to reveal that these siblings may experience a range of feelings, behaviours and interactions. Certain authors describe different experiences and the results of these, for example "unusual opportunities and unusual concerns and needs" (Russel, Russel & Russel, 2003:36), the experience of "disability by association" (Burke, 2004:29), and the development of enhanced maturity on one hand, versus elevated risk for possible psychological concerns on the other (Strohm, 2001:48). More specifically, Meyer and Vadasy (1996:13, 20) and Strohm (2001:49) report experiences of embarrassment and guilt, and Opperman and Alant (2003:450) report experiences of loneliness or isolation. Positive experiences were also commonly reported, for instance pride (Meyer & Vadasy, 1996:21) and understanding and maturity (Dodd, 2004:45). Acceptance of the uniqueness of their sibling was reported by Stalker and Connors (2004:228) who stated that most siblings accepted that we [individuals] are all inherently different anyway. While the studies reveal that the experiences of these siblings may differ, many authors acknowledge the essential need for these siblings to be given support (Burke, 2004; Dodd, 2004; Naylor & Prescott, 2004; Strohm, 2001).

It has been noted that support services focus predominantly on the child with a difficulty, as well as the parents in terms of information provision and support groups (Dia & Harrington, 2006:187; Gorelick, 1996:2). Strohm (2001:48) observes that in the provision of support, a family perspective is often assumed. However, most efforts are concentrated on the parents and the child with the disability. This results in inadequate attention being given to siblings. There is therefore a need to augment and enrich the body of information available to us on these sibling's lived experiences. Greater understanding of their lived experiences is needed to inform the development of support interventions.

On contacting the Down syndrome Association in the Western Cape, I was informed that there are no official support groups at present (Janse Van Vuuren, personal communication, January 22, 2007). Since sibling support was an acknowledged need, attempts had been made in the past to provide a group experience, a "Sibling Day", for the siblings of a child with Down syndrome. Efforts to hold such group meetings were not successful for a number of reasons. Two of these were: poor attendance and the fact that the broad range of ages of siblings made it difficult for

activities to include all and be of interest to all. Van Vuuren reported that support was currently on a more individual basis, for instance individual therapy and counselling. As mentioned above, there is only limited support for siblings of a child with Down syndrome.

When support is provided, Strohm (2001:48) contends that it often claims to be family-centred. However, the focus is predominantly on the parents and child with a disability. Naylor and Prescott (2004:199) and Gorelick (1996:1) share a similar concern: these siblings may become the "forgotten" or "invisible" children when it comes to the provision of support.

In instances when support services have been made available to siblings, such as The Sibling Project in Adelaide (Strohm, 2001:50), findings have shown that siblings reported their relief at being able to talk to someone who is not a family member about their concerns, for example. They learned coping skills, and they learned how others in similar situations felt. They (the siblings) also felt that other siblings of a brother or sister with a disability would be open to attending a workshop.

Strohm (2001:51) reported favourable parental feedback and reflections regarding their child's behaviours and comments since attending The Sibling Project. Similarly, Burke (2004:96) reported that group support gave siblings the sense that someone else was experiencing similar feelings. This was helpful to them and fostered a common identity among them. Two aspects were crucial to the success of support groups: mutual support and sharing experiences within the group (Burke, 2004:97).

It is clear that while qualitative studies have been done on the experience of siblings, there are few studies involving individual accounts, experiences and personal stories, particularly within South Africa. This study provided an opportunity to study individuals, as well as to confirm or dispute the experiences reported by the participants in existing studies. At present, there is only limited information on these experiences, as well as only limited support, specifically in the South African context. This study could usefully augment the information and provide insight into the kind of support that is necessary.

An important aspect that needs to be taken into account when exploring the experiences of a sibling is the societal effects on disability. Society may promote certain views and ideas regarding disability through its pursuits and practices. The

research paradigm, section 1.5.2, discusses social constructivism and the effects of the social context on the individual. An outline and description of the study follows.

1.4 QUALITATIVE RESEARCH

While research on the siblings' experiences does exist, much of this research is quantitative and does not delve into the depth and intensity of the experiences of these siblings. Qualitative research allows the researcher to obtain data that has more depth and detail than quantitative methods makes possible (Durrheim, 1999:42). This approach suited the aims of this study (see Chapter Three for further discussion).

1.4.1 Assumption

It must be mentioned that since I was the sole researcher, I use the first person in this study. Le Guin (1998, as cited in Hill, 2002:4) validates the use of the active voice or first person since this indicates that the author accepts responsibility for the interpretations, details and comments expressed. Jones (1992, as cited in Hill, 2002:4) states that since the researcher is reporting on his or her subjective interpretations, it is in fact an expression of the researcher's reality to use the first person. My own experience, having a younger sibling, must be mentioned as this affected my perceptions. Although he did not have a disability, being aware of my sibling, our unique and differing needs and our relationship and interactions over time, has made me conscious of the profound effects family members exert on each other.

1.5 RESEARCH PARADIGM

An interpretive framework was used in this study. Interpretive methods, as described by Kelly and Terre Blanche (1999:123), endeavour to "describe and interpret" human experiences, rather than measuring these experiences. The interpretive approach is dependent on personal accounts given by participants (Kelly & Terre Blanche, 1999:124). This approach could be used in this study because the participants in this situation were able to use their words to express and describe their life experiences when living with a sibling who has a disability. The theoretical underpinning of the interpretive approach is phenomenological theory (Mertens, 1998:11). An individual's

experience of reality is further discussed with reference to the phenomenological approach.

> *Why phenomenology? Simply because, as humans, we experience before we theorise … To provide a firm foundation for our propositions about objects and subjects, we need first to grasp clearly the lived experience on which they are all ultimately based.*

(Kohák, 1978:3)

As described above, phenomenology seeks to describe how humans experience their world. This approach to human behaviour does not propose that an objective reality exists. Instead phenomenology looks at the individual's reality as a function involving the individual, his or her internal processes and the interplay within their environments. The phenomenological perspective in turn supports an interpretive approach, as it focuses on the reality as experienced by the participant. The interpretive understanding which the researcher seeks is hermeneutic (Eichelberger, cited in Mertens, 1998:11). Hermeneutics is defined in the Oxford Dictionary of Psychology as "dealing with interpretation, especially of literary texts and scripture" (Colman, 2001:329). Danaher and Briod (2005:218) explain that the task of this kind of research is to access the child's articulating of events in their world in their own words. This is often a world forgotten by or unfamiliar to adults.

The interpretative phenomenological approach (IPA) as defined by Smith and Eatough (2006:327) is inductive and aims to produce meaningful, comprehensive accounts of experience. This approach believes the participant to be the authority in describing their experience. The researcher does not have to be immersed in the participant's culture in order to undertake the study, as would be that case with ethnographic research. The interpretive researcher wants to explore "individual and collective understandings, reasoning process, social norms etc." (Mason, 2002:56).

The individual sibling in this study is part of various environments and systems such as school, family, siblings, culture etc, as well as their being at a certain stage of development and living within an era in time. Since the study is situated within a systemic view of society, it looks at experience and inherently involves making connections between experience, behaviour and the relationships with those around us. The effects and interactions among systems are reciprocal, circular and

continual. Experience, although 'belonging' to the individual, is affected by, and will affect others in some way. O'Connor and Ammen (1997:3) argue that any contacts with, and influences on, an individual are an "integral, inseparable part of the system" as this affects the individual's experiences.

Individuals are not passive respondents to the environment and to the internalisation of information. According to Harris and Graham (1994:234), social constructivist theory states that knowledge is developed based on previously attained knowledge. The individual is being created by a situation and culture, as well as creating their contexts, when viewed from a constructionist point of view (Antikainen, Houtsonen, Kauppila & Huotelin, 1996:19). As noted by Mallory and New (1994:325) cognitive activity is always situated in a social context.

A main feature of social constructivist theory states the significance of the socio-cultural environment, as well as the role of social activity in an individual's learning. Therefore, the nature of an impairment or disability will affect how society reacts to and provides for this disability. The social 'treatment' of disability will affect all those close to individuals with a disability. As stated by Damon (cited in Blackford, 1999:673),

> *categories of the world - whether social or physical - are not derived by the child, but are worked out in the course of innumerable social exchanges … thus it is more accurate to say that knowledge is co-constructed by the child in relation to others, than it is simply constructed unilaterally.*

Siblings do not exist in isolation; they are a part of a family and wider social contexts and thus social and familial reactions to disability will in turn affect the siblings' response to disability, their understandings, interpretations, beliefs and views. Antikainen et al. (1996:19) propose that we gain information through our experience of the world and thereafter we use the constructions formed by our experiences. Therefore, human existence is influenced both socially and by the self. As phenomenological theory explains, an individual assigns meaning to life events. This meaning is attached using symbols and language (Antikainen et al., 1996:19). This study explored the unique and particular accounts of individuals (i.e. the accounts of each of the participants in this study), closely examining the expressions, recollections, details and descriptions that the participants constructed about their

personal lived experiences of having a brother or sister with a disability. Although, the siblings in this study are affected by a number of relationships, this study focused predominantly on the influence on one's experiences in life when a brother or sister has a disability. These accounts are their truth and their reality. The following sections discuss the design approach of the study.

1.5.1   Research design

Research design can be seen as the step-by-step plan of the scientific research (Bless & Higson-Smith, 1995:63). In this way it guides the researcher in the collection, analyzing and interpretation of the data. Terre Blanche and Durrheim (1999:6) describe the methodology as the practical specifications for carrying out the study. The design and methodology are briefly described below.

1.5.2   Research Methods

Approaches and techniques that were followed in this study are briefly discussed below. A comprehensive description of the studys' methodology follows in Chapter Three.

1.5.3   Case study

This qualitative study used a case study approach, which provides detail about individuals or particular situations (Lindegger, 1999:255). As Stake (2003:134) points out, the decision to use a case study approach is often dictated by what is to be studied. In this study four cases were identified, which is why the collective case study approach was chosen. The methods used for carrying out the data collection may be selected thereafter.

1.5.4   Participant selection

Participants were identified according to specific pre-determined criteria. This sampling is termed "purposeful" by Durrheim (1999:44) since the participants are judged to fulfil necessary conditions for the study. This type of selection was necessary as certain criteria were vital for the study and thus a limited population group was accessible. The criterion for participation in this study was a family with two or more children, of which one child in the family had a diagnosed intellectual disability. Four participants, the siblings of a child with a disability, took part in this study. Participants ranged in age from eight to fifteen years old. In three of the cases

the child with a disability had been diagnosed with Down syndrome, and, in the fourth case, the child with a disability had been diagnosed with Noonan syndrome. Both of these syndromes affect, to varying degrees, an individual's intellectual levels, social functioning, emotional maturity, as well as impairing physical development and functioning. These disabilities are further detailed and discussed in Chapter Two.

1.5.5   Data collection

The semi-structured interview was chosen as the primary source of data collection. It allows the respondents the freedom to select their own words and descriptions to communicate their observations and interpretations (Bless & Higson-Smith, 1995:107). Secondary data sources included observation, family meetings, in some cases, and a review of relevant literature. Additionally a parent was asked to complete a set of structured questionnaires (See Anamneses: appendices 4-7). These questionnaires provided supplementary personal demographic, developmental and psychological background information about the participant and family.

1.5.6   Data analysis and interpretation

A thematic analysis, within an interpretive phenomenological framework, was used to analyse and interpret data transcribed from the participant interviews. This analysis was an iterative process with certain steps, as described by Terre Blanche and Kelly (1999:141) and Smith and Eatough (2006:333) being followed to assist in elucidating themes. Thereafter, clustering the themes as described by Willig (2001:55) helped connect the 'sub themes' by creating comprehensive or overarching categories.

The above discussion describes the motivation and backing literature for undertaking this study, and the intended research approach for this study. The following is a clarification of certain terms used in this study.

1.6   CLARIFICATION OF CONCEPTS

Clarification of certain terms is necessary to ensure a uniform understanding of their use throughout this study.

1.6.1 Experience

Morgan and King (1975:360) express 'experience' in empirical terms as a key factor, along with learning, which affects our perception of the world. The Little Oxford Dictionary provides a useful and relevant description that can be applied to the experiences described in this study. Experience is defined as "personal observation or contact; event that affects one; knowledge or skill based on this. Verb - have experience of; undergo; feel" (Waite, 1998:222).

1.6.2 Disability

Rutter and Taylor (2002:1115) define disability as "the restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being". This definition of disability implies that socially constructed restrictions and attitudes have a profound effect on individuals with a mental or physical impairment. Further detail on this is provided in Chapter Two. The disabilities affecting this study are those of Down syndrome and Noonan syndrome. Both of these disabilities, which are congenital, lifelong, and present with varying degrees of intellectual and physical impairment, are discussed in detail in Chapter Two.

1.6.3 Sibling

While the term sibling is briefly defined by Colman (2001:675) as being "a brother or sister", a more elaborate definition is provided by Waite (1998:604) as "each of two or more children having one or both parents in common". Both definitions are relevant and applicable in this study. However, it must be noted that a reference to the 'sibling' in this study primarily refers to the sibling that does not have a disability, namely the participant in this study. In certain instances the child with a disability may be referred to as the sibling, but in these cases it is clarified as to which sibling is being referred to.

1.7   SUMMARY OF PRESENTATION OF THIS STUDY

Chapter One presents an overview of the proposed study including the motivation for undertaking this study. The key elements guiding the study, such as the problem statement, the research question and the aim of the study, are addressed in this first chapter.

Chapter Two reviews the salient literature available on the topic of this study. There is very little literature on the lived experiences of siblings of a child with a disability. Furthermore, much of the research in this area tends to use a quantitative approach.

The choice of methodological approach of the study, research design and techniques used in data collection and analysis are explained and discussed in Chapter Three. The rationale for an interpretive approach is related to the theoretical grounding of the study as well as the aims of the study.

While Chapter Three provides the theoretical framework and the course of action in this study, the findings are detailed in Chapter Four. This chapter describes the actual implementation of the study, from initially selecting and contacting the participants to the execution of the research undertaking, its difficulties and complications. Results are analysed and interpreted within the framework discussed in Chapter Three.

The final chapter concludes this thesis by integrating and discussing the findings presented in Chapter Four in relation to the literature review in Chapter Two. The limitations encountered during this study are described and implications for further study are also discussed in the last chapter.

1.8   CONCLUSION

This introductory chapter briefly described this study, from the initial motivation for and the aims of the study to the final data analysis and findings. This includes an outline of the literature review and the methodology used in the study. Key terms are defined in order to clarify their use in this thesis. Finally, the chapter outline gives an overview of the content dealt with in the rest of the thesis.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter explores the literature that informed and guided many aspects of this study. The overall theoretical approach to the study will be reviewed. Disability and the meanings and approaches that are related to the concept of 'disability' are briefly discussed.

Literature relating to the experiences of siblings and families when a child in the family has a disability is reviewed. This has been integrated into the analysis in a later chapter (see Chapter Four). The literature regarding support offered to parents and siblings in these families, and the effects of this support will be briefly reviewed.

2.2 DISABILITY

Disability is defined in the Oxford Dictionary as "permanent physical or mental incapacity; lack of some capacity, preventing action" (Waite, 1998:178). This definition assumes a medical model view and labels the disability as a deficit, residing in the individual. For the purposes of this study disability will be defined according to Rutter and Taylor (2002:1115) as "the restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being". This definition provides a more inclusive view on disability, as it does not suggest that the restrictions are due to the disability, but there may be externally imposed limiting factors.

Gaining information about a disability allows us to develop our understanding on how this disability manifests itself and how it impacts on others in terms of practical additional attention and special care needs, as well as emotional implications. This enables us to relate to the family situation and how its members are affected in terms of care giving, education provision, emotional support and physical assistance needs.

2.2.1 Disabilities relevant to this study

While this study focused on the experiences of a sibling without a disability, by informing ourselves about the prevalence, aetiology, cognitive, behavioural and physical effects of a disability, we gain a better understanding of the areas in which an individual may experience difficulties and consequently how this may affect a family and the sibling. The following section briefly discusses Down and Noonan's syndrome, and their care needs.

2.2.2 Down syndrome

Down syndrome is reported in Rutter and Taylor (2002:226) as "the most common identifiable cause of learning disability, which is typically moderate to severe". The syndrome can be recognised through various means. These may include physical appearance, sensory deficits, cardiac and respiratory defects, genetic variance and cognitive and behavioural phenotype (Rutter & Taylor, 2002:226). The prevalence of Down syndrome, according to de Grouchy and Turleau, as cited in Mash and Wolfe (2002:247) is 1.5 in 1000 births.

Cognitive impairment is commonly associated with Down syndrome, but the cause of the intellectual disability, is not known. Various theories question the developmental instability caused by Trisomy 21, affecting abnormal formation of neural tissue. Another theory concerns the chromosomal imbalance that may have affected vital parts of genetic material (Mash & Wolfe, 2002:247).

Poor eyesight and hearing, as well as heart and lung problems are also associated with Down syndrome. Certain physical features are distinctive in an individual with Down syndrome. According to Mash and Wolfe (2002:247), these features include "a small skull; a large tongue protruding from a small mouth; almond shaped eyes with sloping eyebrows; a flat nasal bridge; a short, crooked fifth finger; and broad square hands …" Features of Down syndrome can differ in degree of appearance and noticeability.

2.2.3 Noonan's Syndrome

According to Cole (1980:468) Noonan's syndrome was first described in 1968.This syndrome shares certain physical features of Down syndrome such as wide set eyes, a short stature and a flattened nose, but is an "inherited autosomal condition"

(MEDLINE editorial, 1992). Varying types of congenital heart defects have also been reported in those with Noonan's syndrome. The nature of this heart disease is a prime determinant in life expectancy of individuals (Ibrahim & McGovern, 2006). The prevalence of Noonan's syndrome according to Ibrahim and McGovern (2006) is 1 in 1000 to 1 in 2500 live births. However Mendez and Opitz (cited in MEDLINE editorial, 1992) state that Noonan's syndrome is "iceberg dominant" since up to 1 in 100 individuals may carry the gene undetected. The cardinal features of Noonan syndrome are unusual facial features, for example, wide set, down-slanting eyes, drooping eyelids and webbed neck (MEDLINE editorial, 1992). About one quarter of those diagnosed with Noonan's syndrome experience mental retardation. Additional afflictions co-exist: "Skeletal, neurologic, genitourinary, lymphatic, eye, and skin findings may be present to varying degrees" (Ibrahim & McGovern, 2006).

A salient common aspect characterises both these syndromes, this is the child's need for increased parental, familial care and support as well as medical attention. About 30 to 40% of infants with Down syndrome suffer from cardiac difficulties; the most common defect is a hole in the heart (Cunningham, 1982:122). Between 60 and 80% of individuals born with Noonan syndrome have "echocardiographic abnormalities" (MEDLINE editorial, 1992).

Both of the abovementioned disorders are present from birth. One parent of a child with Noonan's syndrome writes of the "Warrior Mentality" his little son has had to learn from birth. This father proceeds to mention that this mentality is one that has been adopted by all members of the family (Newport, 2005:21). Similarly, Lessenberry and Rehfeldt (2004:240) state that the effects of these disabilities involve not only the individuals, but also parents. Riesz (2004:380) discusses the emotional, physical, financial, legal and practical effects of having a daughter with Down syndrome. Family, carers and society are affected daily in various ways, as was mentioned above. Increased stress and the needs for support and coping strategies in families when a child has a disability have been inferred in many accounts and studies (Atkin & Ahmad, 2000; Dyson, 1996). Cunningham (1982:28) describes the range of reactions a parent may have when their child is born with Down syndrome, ranging from shock, disbelief, grief to inadequacy, anger, etc. Some parents, through gaining information, know they will be able to manage and

cope, while some parents cannot accept the child and feel repulsed. Although Cunningham (1982:23) points out the difficulty of obtaining accurate figures regarding various reactions, he noted that it is most frequently the condition that is 'unwanted', not the infant. With increased societal acceptance of disability, increased assistance and support exist for parents and families.

2.2.4 Perspectives on disability

"… recognition of the understanding that disability is a form of social oppression rather than belonging to the child."

(Kelly, 2005:262)

As Kelly (2005:262) infers, we need to acknowledge that certain perspectives on disability can be liberating while others may cause oppression. The various models and theories on disability affect society and influence attitudes. A discussion of the perspectives on disability is therefore necessary to understand what influences exist in society. Consequently, in order to inform society and encourage support of those affected by disability; we need to understand where the obstacles to change may lie.

Both external and internal forces shape our attitudes. The media, a dominant external force, is known for its effect on public opinion and attitudes. Nagler (1990) contends that public opinion would have been influenced by the media's primary stance on disability in the past, which tends to be based on the medical model, discussed below.

The medical discourse is a common theory, which associates impairment with disability. Thus, this construction may label the individual as disabled and this is "the objective attribute" that defines the individual (Engelbrecht, Green, Naicker & Engelbrecht, 1999:13). It is thus often viewed as a discourse that focuses on pathology and disease. The medical model does, however, have its place. Its use in diagnosing and classifying disorders and disease is vital in the support and prevention thereof, as well as in providing information on pathology. It is therefore essential for effective and properly managed health care. However, the medical model becomes less useful, and can be destructive, when labels become limiting, and the individual's disability becomes all encompassing (Burke, 2004).

As Burke (2004:18) states, the social model of disability recognises individual difference as a part of life and does not promote exclusion, on the grounds of a disability, as a beneficial solution. He reasons that individuals become 'immobilised' or hindered when the environment does not adequately provide for them. Those individuals with impairments and disabilities then effectively become "disabled" due to barriers that arise or exist externally. Thus through ensuring society recognises the diverse needs of all, and caters for all members in society, the disabling consequences of impairments will be lessened. People's attitudes can pose a prominent barrier. Research and information can assist in influencing this barrier, and more so with the help of relevant and useful media publicity.

There are other perspectives on disability. Baumgart (1992) discusses the 'different person' and the 'rights' perspectives. These perspectives debate the inevitable differences between individuals versus the rights that every individual should be afforded without exception. Disability should not limit the rights of any individual. Promoting understanding, as quoted below, can assist in this process.

> *"Increased understanding leads to changes in the perceived social acceptability of children with learning disabilities."*

(Hames, 2005:3)

While having briefly looked at certain perspectives on disability we are able to reflect on the models that may lead societal views and affect social perceptions. These perceptions shape attitudes toward those with a disability and their families. Kelly (2005) noted that exposure to the ideas about and perceptions of disability that other people have influences the disabled child's own interpretations of his or her disability. We then see how "popular" or public opinion can have a profound effect on those with a disability, and consequently their families. An aware and informed public can in turn affect the support, care, interventions and recognition given to those affected by disability. Knowledge is strongly affected by social contexts and influences that provide these experiences. Societal views and demeanour toward impairment influences and affects the siblings of those with disabilities. Through information, we have an opportunity to open minds and decrease the restricting effects of disability for all concerned.

2.3   BRIEF DISCUSSION OF LITERATURE: THE EXPERIENCES WITHIN FAMILIES WHEN A CHILD HAS A DISABILITY

Various studies have been conducted on the effects of disability such as Down syndrome, Autism, and chronic illness on families. These studies, mentioned in Chapter One, have looked at the effects of disability on various aspects of the family experience and functioning. However, some studies although claiming to use a systemic approach, tended to look predominantly at the effects on parents while taking little account of other children in the system (Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005).

Research looking at Taiwanese mother's perceptions of their infant with Down syndrome, mentioned the context of the family and culture on parenting. Siblings, however, were only mentioned in the discussion of certain cases when describing the family situation (McCollum & Chen, 2003). Another study on a mother's' expressed emotion towards her child with Down syndrome (Beck et al., 2004) looked at differences between the mother's expressed emotion towards her child with an intellectual disability and towards her non-intellectually disabled child. While this study included the non-intellectually disabled sibling in the research, there was little mention of the effects of this expressed emotion differential on him or her.

Most of the studies referred to above are quantitative in their approach. These quantitative studies tend to look at the behaviours and external manifestations that can be directly recorded and thus quantified. There are, however, relatively few qualitative studies that look at the experiences, meanings and perceptions that individuals apply to their lives and situations, and how disability may have affected them during their life and their experiences of this.

From the above literature it is clear that while there is research on disability related to siblings, families and their relationships etc., this research is predominantly quantitative. By using a qualitative approach the meaning and feelings experienced by individuals are explored. More specifically, this study explores the siblings' experiences in a family where childhood disability exists.

2.4   THE FAMILY

Ackerman (1961:39) describes the stability of a family by comparing the family members to marbles. These marbles line the bottom of a bowl and thus form the sensitive foundation of emotional balance and interchange within the family system. The insight provided by this description makes it clear that a brief discussion of family systems is necessary.

The individual exists in various systems as described in systems theory (O'Connor & Ammen, 1997:3). Children are born into a family system. Their experiences are thus shaped by the parental, spousal, sibling and family subsystems that surround them. While the approach of this study assumes a phenomenological underpinning, it must, however, be mentioned that awareness of the systemic effects is useful in a discussion of experiences. Interactions between the child with a disability, a sibling, a parent, and the family as a unit within the wider social system will affect one's experiences. O'Connor and Ammen (1997:1) note that developmental and historical effects are intrinsic in the systemic approach. This systemic perspective illustrates the interdependencies that, over time, occur within and between the individual, family, peers, the social environment and the macro environment. Both the environments and the function of time affect the dynamics of relationships as well as societal attitudes towards disability.

Through looking at the family system we learn about the roles and responsibilities that exist within a family. Dallos (1991:76) notes that with the continual transforming of systems, an attempt at system "coherence" is maintained, in this case the coherence of the family system. As an example we could consider Strohm's (2001:48) findings of the often, warranted but disproportionate time spent on the care and support of a child with a disability, and often at the expense of the child with no disability. Dallos (1991:19) maintains that attempts to preserve family coherence can cause the resistance of change in certain areas. This could result in less time being spent with children who do not have a disability since they seem able to look after themselves. This resistance to balance must have an outlet in other areas. 'Power struggles' may be an area in which we see this manifested. As explained by Dallos (1991:76), problems arise as a consequence of a child's attempts to influence or exert control over a parent. A sibling may consider time spent with one child as

'wielding more power' over parents' affections. Dallos (1991:76) suggests that a child's sulking and throwing tantrums might be attempts to divert a parent's attention to him or herself. Mattheis (1999:39) stresses that a parent should aim to ensure equal attention is paid to each child in order to maintain stability in the family. Parents may be aware they are investing more time with a certain child; this can lead to their reported feelings of guilt regarding neglect. Dyson (1996:283) argues that the sibling's expressed resentment of the time parents spent with the child with a disability is an indication of the needs of the other children in the family.

Studies by Lessenberry and Rehfeldt (2004:240) and Dyson (1996:284) report overall increased familial stress in a family in which a child has a disability. As Kramer and Kowal (2005:503) note, the quality of family life is significantly influenced by the degree to which children in the family get along. A study by Dyson (1996:285) supported findings of other studies that the self-concept of a sibling of a child with a disability was not necessarily adversely affected. Nevertheless, the family system can have profound effects on the sibling and vice versa. Families may have differing routines and the quality of sibling interaction may be affected by disability in the family. To better understand this we need to consider the sibling relationship in the family system.

2.5   THE SIBLING RELATIONSHIP

2.5.1 Interactions

Time can be spent in many different ways. The way, and with whom we spend our time will affect our experiences. As depicted below, children spend time with different people in their daily activities.

Children's companions in their daily activities.
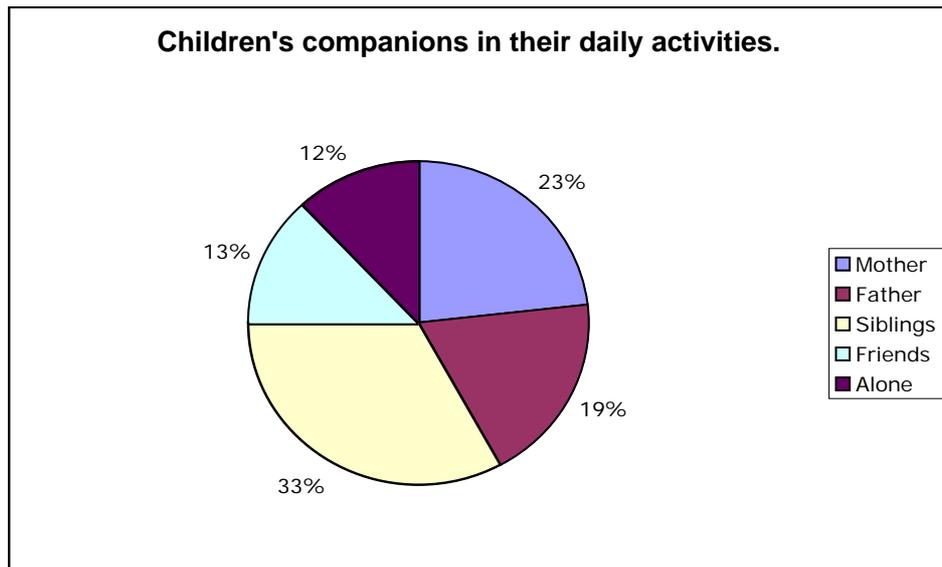
Figure 2.1

(McHale & Crouter, 1996:173)

Dunn and Plomin (1990:94) contend that apart from the obvious direct effects of spending time with a sibling, the mere fact of having a sibling, another person who differs from you but is similarly reliant on parental involvement, is a profound experience in itself.

> *There is another, less direct way, in which the presence of the sibling may lead to very different, developmentally important experiences for two children growing up together. It is not solely through the direct experience of interaction that the influence of a sibling can be felt by the other child. The continual presence of another child different from oneself, a child whom one knows all too well, and with whom one competes for parental affection and interest, can be profoundly important in the development of a sense of self, of emotional security and of understanding others.*

(Dunn & Plomin, 1990:94)

Dunn and Plomin (1990:94) note the more inherent effects of having a sibling. The fact that siblings spend the majority of their time together must affect the lived experiences of these siblings.

Dunn and Plomin (1990:95) also looked at two issues when discussing sibling experiences in the family system. The child is aware of their sibling's personality, their relationships and their successes. This first, personal, evaluation can also be in terms of parental attention given to the other child, especially if at the cost of time

spent with another child. This internal, private comparison may have an impact on self-esteem. The second, external evaluation is a social comparison. The "impact of another's opinion and evaluation of oneself" also plays a major role in individual self-esteem and evaluation (Dunn & Plomin, 1990:95). Naturally, because of differences in all siblings, these appraisal and 'self esteem affecting' processes will be different for both siblings in a family. The difference in these evaluations will result in different experiences for each sibling. It has been reported that siblings are able to clearly report on the differences between themselves and their sibling (Dunn & Plomin, 1990). That study was concerned with the effects of the differential experience of siblings when *neither* child has a diagnosed disorder or learning difficulty. It is thus necessary to look at the experiences when the differences between siblings are more obvious and profound, as with when a brother or sister has a disability. In this case the evaluative components of the child without a disability may become more pronounced, and the family dynamic and parental treatment must vary in some way to influence effects on self-esteem. As previously mentioned, Meyer (1993:1) sees the sibling relationship as possibly the longest lasting relationship we experience in life. Therefore, the experience of the sibling relationship and interactions can have a profound effect on an individual.

Research by Caro and Derevensky (1997) on the interactions between siblings where one was disabled found that there were largely positive interactions. The non-disabled sibling maintained interactions for prolonged periods of time, but that there was variability in the activities chosen as the non-disabled siblings tended to choose activities that they preferred. The non-disabled sibling attempted to encourage their sibling to attend to the activity. These attempts ranged from great to little effort. From the above it is apparent that these interactions between a disabled and non-disabled sibling, although varying, rely more on the non-disabled sibling's efforts to engage with his or her brother or sister. However, the response of the disabled sibling affected the further intensity of efforts to engage in activity. The age of the non-disabled sibling was a factor in sustained effort. Younger siblings showed less perseverance, while the older siblings made an effort to engage in interactions for longer periods (Caro & Derevensky, 1997). Thus the responsibility for initiating and maintaining interaction seems to be generally assumed by the sibling without a disability.

Most sibling relationships are two sided. McHale and Gamble (1987:132) note the inevitable effects of the sibling relationship on a child's social, emotional and mental development, and thus the particular consequences when one sibling has a disability. Siblings often spend large amounts of time together and what can be a harmonious relationship at one stage and in one situation can be a source of anger, distress and anxiety in another situation. Alternating between the roles of rival and opponent versus supporter and ally is a standard occurrence (McHale & Gamble, 1987:133). While being playmates, siblings may also take on the roles of leaders, teachers and caregivers (Burke, 2004; Caro & Derevensky, 1997; McHale & Gamble, 1987).

Sibling relationships differ according to the stage of development. It appears that sibling relationships experience more negative ratings as children grow up. As noted by McHale and Gamble (1987:150), adjustment problems tended to correlate with increase in age, and problems were more internalised in the adolescent stage. Both these statements impress the necessity of early support, but support at any stage indeed. Through insight into the child, or siblings' experiences, support efforts can be developed and enhanced.

2.5.2 The experiences of siblings

Studies have looked at the experiences of siblings of children with physical and cognitive disabilities (Dodd, 2004; Pit-Ten Cate & Loots, 2000), chronic illness (Wallinga & Reed, 1990) and diagnosed disorders (Kaminsky & Dewey, 2001). These studies give us some idea of the experiences, as reported by siblings. Certain of the studies, discussed below, have varying outcomes and findings in terms of experiences. Whereas some studies report that there is no significant difference between the reported well-being of siblings whether they have a sibling with a disability or not, others report appreciable differences in relation to these experiences. There are commonalities in experiences and feelings in several studies. However, every child will experience their situation differently.

A recent study by Ligthart (2002:71) looked at the lived experiences of a child when a sibling has a disability. Certain main themes were extracted. The following themes of sibling experiences were mentioned as central themes: insecure and anxious feelings; attention seeking behaviour to attain control; anger, sadness, and

aggression toward the disabled sibling. In a study exploring the 'well' sibling's adjustment when his or her sibling has diabetes, Hollidge (2001:20) noted that siblings reported unhappiness, sadness and distress about their siblings' illness. They also felt it necessary to reduce 'unacceptable' feelings of jealousy, anger and competition. This results in internalisation of feelings. Turning these feelings inward can result in the experience of shame. The most significant feeling reported by 'well' siblings was that of guilt. Additional feelings of worry about health, their own and their siblings' was also a central experience.

Experiences are not essentially negative. Meyer and Vadasy (1996:21) report that children sometimes feel proud when their sibling with a disability learns something from them and that they experience relief when others understand the difficulties their sibling may have. Russel et al. (2003:36-37), speak of "unusual concerns and needs" as well as "unusual opportunities", which indicate the positive as well as the negative aspects that may be experienced. The finding of both positive and negative experiences is supported by studies by Pit-Ten Cate and Loots (2000:402) and Wilson (2004:90). Burke (2004:86) notes that predominantly positive experiences were experienced by younger siblings, and were characterised by the acceptance of the disability within the family. In discussing the issue of accepting siblings 'as they are', Stalker and Connors (2004:228) state that most participants did not see disability as something to be amended or altered and regulated. Siblings acknowledged their brother or sister's uniqueness and recognised them as individuals. In this sense, they ARE different and thus "like everyone else". In addition, Smith, Greenberg and Seltzer (2007:36) found that siblings were willing to assume a key role in assisting their brother or sister in the future. They were also aware that they might be responsible for sustaining family bonds by way of visiting regularly and ensuring time together during holiday celebrations.

A study by McHale and Gamble (1987:133), asked siblings, aged between 8 and 14 years, of disabled children as well as non-disabled children to rate "how happy they were" on various dimensions. These were: time spent with sibling; time spent in care giving; how siblings get along; how much the sibling without a disability is boss; parents' treatment of child versus sibling without a disability; overall satisfaction with relationship. According to this study, it appeared that results were similar in

experiment and control groups on most of the above scales, although significantly higher ratings on the dimension of 'getting along', were given by the siblings of a child with a disability.

McHale and Gamble (1987:135) extended their study to look at conflict interactions. A daily telephonic interview was held each evening with the sibling without a disability. This allowed the child to recount his or her sibling interactions that day. Again no significant differences were found between siblings of disabled children and non-disabled children. Gender did, however, appear to influence the reports of siblings' (with a disability) negative behaviour toward their brother or sister, with girls reporting this more often. It was also found that adjustment problems are more highly associated with being an older sister of a child with a disability. Suggestions that this was related to increased care giving requirements were made. Implications of the 'carer' role are discussed later in this chapter.

Nine of the categories relating to the 190 problem incidents described by the sibling during the telephone interviews described above were elucidated These categories can be described as experiences of: child with disability behaviour being different or weird; child with disability being hurt or sick; child with disability does something negative to sibling; sibling does something negative to child with disability; child and sibling are mutually negative; child with disability is naughty; sibling is concerned about the child with disability's emotional well-being; sibling can't do something because of child with disability; child with disability gets upset even though sibling hasn't behaved negatively. Once again findings between the experiment and control groups were similar, notable differences only in the areas of when a child with disability was hurt or sick, and this enhanced the sibling's concerns about a child with disability emotional well being. When the sibling was not disabled, as in the control group, the problem of mutual negativity was reported as more significant than the group with a disabled sibling (McHale & Gamble, 1987:137). This raises the question about whether the sibling of a child with a disability may assume responsibility to evade conflict situations and perhaps internalise his or her negative reactions.

Strohm (2001:49) notes several areas in which siblings experience concerns and issues with relation to their brother or sister with a disability. They experienced:

- A fear of having or developing the same disability as their sibling, namely identification with the disability;

- Guilt feelings about having caused the disability and/ or 'survivor guilt' about not having a disability;

- An ongoing and varying need for information regarding the disability;

- Pressure to be the child that does not add to parental concerns, they may conceal or deny their worries;

- Belief that they must do well academically to make up for their brother or sisters inability to perform;

- Guilt over own skills and capabilities;

- Feeling resentful if less attention is given to them than their sibling with a disability;

- Feeling embarrassed regarding the appearance and/ or behaviour of their sibling;

- Low self esteem resulting from shame regarding negative feelings;

- Greater or more responsibilities and care giving tasks;

- Worries about the future - this concern may be with regard to their own children one day as well as future care responsibilities regarding their siblings;

- Feeling alone or secluded in cases where there is only the one sibling.

Meyer and Vadasy (1996:8-31) confirm these experiences of siblings in families where a child has a disability or has special needs. The additional experiences they report in this literature were:

- Feeling angry at a sibling's behaviours

- Accepting differences

- Feelings of guilt and self blame for negative feelings at or about a sibling

- Feeling jealous about wanting more time or attention from significant others

- Assuming roles that are not a sibling's 'job' in the way of caring and taking on tasks

- A capacity for understanding others in difficulty

- Feeling embarrassed in public

- Experiencing pride at a sibling's accomplishment

- A sense of loss about aspects of the sibling relationship that are not unattainable

- Enhanced maturity, for example wisdom and strength

- Identification with the disability, concerns about also having the disability

- Distressing concerns regarding the sibling with a disability, with regard to being hurt i.e. accidents

- Issues and concerns regarding his/ her future

- Feeling different, misunderstood, alone and unhappy.

The extent and range of experiences noted above varies and every individual's experience is unique. Identification, as mentioned above, appears to be a central experience in many studies. This can cause the children to believe they are themselves in someway affected or have a disability as well. McHale and Gamble (1987:148) claim that this usually occurs when children are closer in age and are treated in similar ways. They also mention that the developmental stage of Identity formation can be affected by this identification. The formation of identity is strongest during adolescence, according to Erikson's theory of development (Louw, van Ede & Louw, 1998:53) and thus has implications for support needs at this stage of a child's development. Burke (2004:29) adds that the experience of living with a disabled sibling can in effect be experienced as 'disability by association'. He explains that social attitudes and the 'treatment' of disability, in conjunction with the life changes and consequences of disability in a family can reinforce this association of being disabled. Opperman and Alant (2003:450) note the adverse effects of the experience of uncertainty. They state that coping ability may be affected by this uncertainty and suggest that communication of sufficient clear and true information regarding their sibling's disability can aid coping responses and reduce ambiguity and uncertainty. This communication can also clarify the responsibilities and roles that should or

should not be assumed by siblings. The assumption of roles, sibling interactions, reactions and behaviours are all related to a child's experience, and warrants further discussion.

2.5.3 The roles played by siblings

Tucker, McHale and Crouter (2001:268) studied the experiences of siblings when *neither experienced disability*. According to this study, age, or rather birth order, can define some of the responsibilities taken on. The younger sibling saw the older sibling as a source of support regarding non-familial concerns. These included areas of social and scholastic activities. The older sibling also viewed himself or herself as playing this supportive role. Both siblings felt equally responsible when it came to support with regard to familial concerns. However, the younger sibling, when more proficient in their competence in peer relations would give support to the older sibling in the area of social life. It appears the interactions and responsibilities are legitimised by age and ability in these families. Thus when addressing the experiences of a sibling in a family when a child does have a disability these 'birth order' related roles and responsibilities must be taken into account.

According to Caro and Derevensky (1997) when looking at roles assumed by siblings in a family when a child does have a disability, responsibility in leading interactions seems to fall more on the non-disabled sibling. This directive role in this study was classified into four types: the teacher, the manager, the helper and the provider of stimulation. The disabled sibling tended to take the role of learner, manager and helper, or no role was assumed. The disabled sibling at times assumed combined roles such as the role of equal playmate and teacher. As suggested in this study by Caro and Derevensky (1997), the higher incidence of directive roles could be due to the requests of parents for the sibling to assist in care giving for their disabled sibling. The 'role choice', made by the disabled sibling was another suggestion made for the 'leader and follower' roles. This suggests that the sibling with a disability takes on subservient roles and this in turn promotes the 'dominant' role to be taken on by the non-disabled sibling. Along with a dominant or leadership type role comes added responsibility as a consequence.

> *Both for the sibling who is leader/ teacher and for the follower/ pupil sibling these experiences are likely to be important. We know that it is not only the experience of being taught that can have developmental consequence: the experiences of explaining and confronting the puzzlement of a mind less mature than your own can be a formative one intellectually.*

(Dunn & Plomin, 1990:93)

Dunn and Plomin (1990:93) emphasise that sibling relationships and roles can have developmental effects on any child.

2.5.4 The role of the young carer

Burke (2004:69) speaks of "young carers". It can be reasonably expected in any family that a child or children take on caring responsibilities. However, a sibling can become a young carer when he or she provides help additional to that which is normally expected when a child in the family does not have a disability (Burke, 2004:69-70). The siblings of a child with intellectual disability, when compared to those siblings of children without intellectual disability, reported elevated levels of 'helping behaviours' in the areas of emotional support and perceived 'guardian' type care (Hannah & Midlarsky, 2005). McHale and Gamble (1987:139) noted a difference in sibling roles or activities depending on whether a sibling had a disability or not. The child with a disabled sibling tended to spend predominantly more time in the role of a carer. When neither sibling had a disability more time was spent doing chores together. It appears that the roles assumed by or expected of siblings can lead to difficulty when their own needs and emotions are subordinated to those of others. Role reorganisation can occur when the younger sibling is more able than the older. This 'role tension' is the result of the child with a disability becoming 'the youngest' in the family, regardless of chronological age. Younger siblings may be required to subordinate their needs to and provide care for their disabled sibling (Faber & Rykman, 1965, cited in McHale & Gamble, 1987:148).

Parentification occurs when a child assumes parental roles. Caro and Derevensky (1997) explain that this unequal role occurs when a child is assigned either a role of dominance or obedience by the parent. Self-blame results when a child attempts to fulfil a caring role that is not achievable. If family members also expect the child to play this role, guilt and other emotions can result (Byng-Hall, 2002:377).

A study involving naturalistic observations noted the sibling variances in roles, behaviours, and interactions. Caro and Derevensky (1997) observed the interactions between siblings with and without disabilities. They noted that the non-disabled sibling more frequently took on a directive role. The equal or a submissive role was less often assumed. Stoneman, Brody, Davis and Crapps (cited in Caro & Derevensky, 1997) argue that this directive role might be due to parents' expectation of assistance by the sibling of the child with a disability, suggesting that this more "assistive" role may result in sibling conflict. Consequently it may require specific parental effort to make the development of more evenly balanced roles among their children possible (Caro & Derevensky, 1997). Differential treatment and expectation was apparent in the parenting of these siblings. While more qualitative, this study was based on observed behaviours, not on experience as reported by the individual.

2.5.5 Differential treatment

This brings the concept of differential treatment of siblings into play. It is worth considering whether parents perceive their parenting as differential. Do parents recognise the child's perception of unfairness at times, or is their additional time and attention spent with a child with a disability accepted as 'legitimate' within the family? Research using parental reports of differential sibling experience noted that the common response of parents was that they do not treat their children differentially (Daniels & Plomin, 1985:758).

In looking at the sibling's experience it is necessary to determine whether the child experiences it as such. It appears that the answer varies. Dunn and Plomin (1990) report that it was notable that siblings, one with and one without a disability, reported their personal differences to be far greater than the differences they experienced in parental treatment. McHale and Pawletko (1992:74) looked at sibling relationships and childhood adjustment in two family contexts, families with and without a child with a disability. Measures for maternal, not paternal, involvement were looked at. They noted in their findings that in families with a disabled child, a greater experience of differential treatment was present. Fisman et al. (2000:374) note that the perception of differential treatment has a greater influence on siblings' adjustment than does the actual sibling relationship.

McHale and Pawletko (1992:74) highlight the significance of the perceived legitimacy of this difference in treatment when it does occur. Children who perceived that there was a legitimate reason for a difference in treatment by their mother were reported to be less vulnerable to the effects of the differential treatment. While some sibling concerns and issues may be internalised, as is discussed later, the sibling's ability to cope or feeling of distress is reflected to some extent in his or her behaviour.

2.5.6 Behaviours and reactions

In their findings Caro and Derevensky (1997), note that the sibling without a disability demonstrates both positive and negative behaviours towards his or her sibling with a disability during interactions with each other. Positive behaviours classified were: physical closeness, verbal interactions, prolonged participation in activities together, and varying levels of enjoyment. Examples of negative behaviours were noted as: intolerance, teasing and taking no notice of the sibling. The inability to understand another's situation or standpoint (33%), followed by unsympathetic and derisive comments (30%), were the highest negative behaviours displayed by the siblings without disabilities. A relatively high percentage of non-disabled siblings (17.3%) demonstrated no interaction with their brother or sister. This study did not offer an explanation for this non-interaction, however it was noted that age of the non-disabled sibling did not appear to influence this, as participants ages ranged from three to twenty years. Assistance with care (27%) was the highest positive cognitive behaviour recorded (Caro & Derevensky, 1997). This caring role is described as a positive behaviour in the above study but the implications of this caring role, as previously discussed, can create difficulties.

Observed reactions can give an indication of the experiences that a sibling may be dealing with. McHale and Gamble (1987:138) distinguish four categories of coping behaviours or sibling reactions to a brother or sister with a disability. These include physical hitting of or yelling at a sibling, removing oneself from the situation in order to forget about the problem, self-instruction to ignore the sibling or allowing oneself to have mean thoughts about the sibling.

These above reactions were further examined in terms of efforts that were directed internally or efforts that were directed externally. McHale and Gamble (1987:139) noted that the lowest anxiety provoking response, to "try and do something fun to

forget the problem", was the least used response. This can indicate the possible need for, and the potential value of skills development or enhancement in support programmes.

Ross and Cuskelly (2006) looked at sibling adjustment when a brother or sister had Autistic Spectrum disorder (ASD). They found that aggression appeared to be the most prevalent problem in interaction within the sibling dyad. However, they doubted that this represented typical sibling interaction, feeling that it might not specifically represent the sibling interaction when a child has ASD (Ross & Cuskelly; 2006:83). This study reported anger as the siblings' most common response to aggressive interactions caused by the child who has ASD. Ross and Cuskelly's (2006) found that internalising behaviours fell within the normal range. This finding was challenged by the accounts of the participants' mothers who reported that these siblings have significant adjustment difficulties and do internalise problems (Ross & Cuskelly; 2006:84). A study by Fisman, Wolf, Ellison and Freeman (2000), and findings by Gold (as cited in Ross & Cuskelly; 2006:83) substantiated the mother's reports that depression, internalising and externalising behaviour problems were significant in the siblings of a child with a pervasive development disorder.

Similarly McHale and Gamble (1987:141) argue that internalised reactions may result in emotional difficulties. Siblings appear to internalise their problems, such as worries about the well-being of their disabled sibling. This includes future concerns about what will happen to a brother or sister when parents are no longer around to care for them.

2.5.7 Questions about the future

Siblings' questions about the future indicate the concerns that weigh on their minds. Meyer and Vadasy (1996:111) report that these questions involve issues such as where siblings will live when they grow up, who will care for them, and if they have children will their children also have a disability? Open, realistic and honest discussion about these questions could allow siblings to reveal their concerns and perhaps receive answers to these very real issues.

From the selection of studies above, we can see the extent, range and complexity of emotions and concerns that are experienced by these siblings. In the available literature experiences related to difficulties appeared to outweigh those of a positive

or beneficial nature, although constructive valuable experiences were reported. Experiences were affected and compounded in many ways, and were undoubtedly related to the individual context. The coping skills he or she has, the family system, school, peer environments etc. will all affect the child's experiences, and consequently his or her reactions. Support from parents, school and peers may afford a sense of validation and assist a sibling to feel that he or she is not alone. Listening to concerns and questions and providing open communication are beneficial first steps in supporting a child and promoting resilience, as discussed next.

2.5.7.1   Resilience and coping

When looking at experiences, of any sort, we need to consider the influences that may affect the intensity of experiences. In this study, it must be mentioned that resilience and coping skills can have a large impact on a sibling's perceived experiences. What may appear as unfair treatment and cause distress in one child may result in cognitive understanding and thus easier acceptance in another child.

The notions of resilience and coping introduce the asset-based approach, which deserves mention in this study. Kaplan (2006) notes that resilience has proved a difficult concept to define precisely due to the intricacies of situational, theoretical and conceptual issues. Resilience can, however, be broadly defined as persistent constructive adaptation to adverse and challenging situations and contexts. The role of risk should also be included. Risk can be described as the concept that exposure to certain situations can predispose a person to an adverse result (O'Dougherty Wright & Masten, 2006:17-19). Strohm (2001:50) mentions variables that can affect resilience, the adjustment, coping and the quality of life of siblings. Variables she referred to are; age, family socio economic status and parental attitudes and expectations. It was also observed that difficulty increases for the sibling if they are younger than the child with a disability and if there are no other siblings in the family. Adjustment can be related to coping in that the difficulty to change may result in further vulnerability. Experiences of injustice, unfairness, difficulty and anxiety may cause distress. Older sisters were found to be more vulnerable, as were younger siblings of older disabled children. Older brothers of a disabled child showed more anxiety as well as poorer perception of their conduct and social competence (McHale

& Gamble, 1987:147-148). Fisman et al. (2000:373) noted that factors that promote resilience, namely protective factors, in siblings of children with Down syndrome are sibling warmth and lower conflict. However, they also warn that the sibling relationship is complex, and a number of other factors affect coping, for example, differential treatment, as previously mentioned.

According to many studies, as discussed above, siblings of a child with a disability can, in certain circumstances, be considered at risk for elevated anxiety, emotional and mental health conditions (Fisman et al., 2000; Hollidge, 2001; Mattheis, 1999; Strohm, 2001). Studies by both Dyson (1996) and Strohm (2001) noted parental recognition of a need for the support of the siblings. However, while these needs were apparent to the parents, they were not always easy to deal with by the parents: time, emotions and energy become scarce resources when tending to a child with a disability. It must also be noted that many siblings will report and present no, or few, issues or concerns. This presents us with the matter of effective support interventions that are relevant to the siblings' needs, and consequently foster the development of resilience and coping skills.

2.6 SUPPORT PROGRAMMES

There is no requirement that clinical levels of pathology must be met in order to provide care and support. The mere fact that a child may be exposed to adverse or difficult situations warrants support (Gardner & Smyle cited in Burke, 2004:97). Ideally, a child should receive support as a preventative measure rather than after referral.

Support in a child's life can come from many sources. The provision of community support programmes can allow the child to feel that others outside the family share experiences and concerns and this can alleviate the feelings of isolation and guilt (Burke, 2004:97). When this support does not exists the responsibility falls heavily on the parent to provide the most effective support in their power. With this comes the necessity of understanding their children, their experiences, and their needs. Supporting parents and providing them with information is a crucial step in providing support for any child. With this in mind we can turn to those who have daily interaction with, and thus affect the child, their parents.

2.6.1 The parents' power

Through determining the predictors of positive social behaviour in children, and the consequences of this on their sibling relationships, we can more effectively advise support programmes and reinforce and encourage the building of positive relationships between siblings, especially useful when one child has a disability. A study by Kramer and Kowal (2005:508) looked at siblings' maternal relationship and relationship with peers prior to the birth of a sibling. This study indicated that social competence and effective relational skills in later life may be associated with early childhood learning and implementation of social skills and behaviours. Being able to effectively manage companion relationships from a young age may assist later in promoting positive sibling relationships. Thus developing certain levels of social skills at a young age can aid in further relationships within the sibling system.

Kramer and Kowal (2005:509) state that it is important to understand the origin of sibling negativity since this negativity can lead to future antisocial behaviours. These findings, indicating that poor early socialisation resulted in externalising behaviours, are relevant to this study as the experience of the sibling relationship can be enhanced through early peer intervention and maternal interaction or support, especially if the sibling without the disability is the older child. This in turn bodes well for the family in terms of the older sibling's developing apt social skills, as well as the sibling relationship quality into adolescence.

Brooks (2006:301-311) turns to the parents to discuss the effects and power that they wield over the positive development, resilience, of their children. He talks of a "resilient mindset" and provides "guideposts" that a parent can follow to nurture resilience in their children. These pieces of advice can provide useful tools for any parent of any child, whether disability exists in the family or not. Parents can affect a child's experience, and thus these ten suggestions can provide practical tools to foster resilience and enhance an individual's ability to cope in adverse times.

These guideposts are as follows:

- Being empathetic

- Communicating effectively

- Changing negative scripts

- Loving our children in ways that make them feel special and appreciated

- Accepting who our children are and helping them to establish realistic expectations and goals

- Helping our children experience success by identifying and nurturing their 'islands of competence'

- Helping children realise that mistakes are experiences from which to learn

- Developing responsibility, compassion, and a social conscience by providing children with an opportunity to contribute

- Teaching our children to solve problems and make decisions

- Disciplining in ways that promote self discipline and self worth.

2.6.2   Contact and communication

It is clear, from the suggestions given above, that communication is vital. In addition, providing clear and truthful information is important. McHale and Gamble (1987:150) noted that withholding information from children, even in the belief of protection, can allow the child's imaginings to become extreme and more distressing. At certain developmental ages, egocentricity and magical thinking can led to blame, of self or another, and unnecessary guilt being carried by the child.

The need for information is supported by Hames (2005:16) who found that the siblings from families that promote open discussion about a child's disability in the family develop a beneficial understanding of the disability. Siblings that feel able to ask frequent questions, listen freely and observe, gain a realistic understanding regarding difficulties their brother or sister is experiencing. This may advance their social awareness with respect to disability. Parents should therefore be open and truthful in answering questions about other people's reactions toward the disability.

2.6.3   The contribution of support programmes thus far

In support of the above recommendations for open communication, Strohm (2001:50), identified four significant needs, namely; the need for clear information; the opportunity to speak candidly about their emotions; one-on-one quality time with their parents; and support and help in developing internal resources to effectively manage and deal with feelings such as guilt, anger and embarrassment. Similarly,

McHale and Gamble (1987:152) report that the primary goal of effective support efforts is to allow a child to know that their feelings, concerns, fears, coping problems etc are normal and to provide these children the space to express, communicate and share these feelings.

Support programmes that have been carried out in the past have consisted of discussion groups, books, and newsletters for parents and siblings. McHale and Gamble (1987:131) argue the importance of interventions to foster positive sibling interactions. Support includes behavioural training in managing and coping with the disabled child, sibling support groups, and parent education programmes designed to foster understanding of the special needs of these youngsters. The opportunity to express feelings and needs openly was offered by Strohm's "Sibling Project", Adelaide, Australia, 1999. This was a pilot exercise to co-ordinate support efforts for siblings. Through the input from the siblings, both adult siblings and children, of an individual with a disability, the primary need identified was that of 'contact'. Specifically, the need to meet with others who are in similar situations, and whom they can relate to was reported as the most beneficial form of support (Strohm, 2001). Burke (2004:96) reported similar findings with respect to need for contact and open communication with those in similar situations. This helped one child realise she was not alone in her experiences. Recognition of a common identity was seen as one of the strongest benefits of a group support programme. Despite the group's reason for being initiated, i.e. 'origin of similarity', the group established these siblings' rights as individuals in their own right, apart from the disability.

Both Meyer and Vadasy (1996) and Mattheis (1999) noted the possible choice of respite care as a form of support for the family. This allows parents and families anything from a few hours to a few days of rest. A qualified individual or an institution can provide the necessary care and stimulation for the child with a disability over this time. The benefits include the reduction of burnout in a family. Respite care or institutions can, however, be difficult to locate and may be costly. Thus it is apparent that support is necessary. Support for families, carers, siblings and the individual with a disability. This is, however, not always forthcoming.

2.7   CONCLUSION

This chapter looked at the literature on many aspects of the sibling experience with relation to intellectual, physical and developmental disabilities. While the behaviours, interactions, roles and feelings of the siblings were discussed, there was little investigation into the attributions that these siblings made regarding their experiences. This may tie in with the scarcity of research that looks more deeply into, and explores qualitatively, the individual's experiences. From available literature it appears that although experiences can be both positive and negative, they tend in many cases to cause some degree of difficulty for the siblings of a child with a disability. The role of the parent in supporting their child was acknowledged as paramount. With this in mind support was necessary for the whole family, especially for parents, but not at the exclusion of the sibling. The provision of support and programmes to develop resilience in a child is necessary as this offers a way forward in the development of resilience through effective coping skills.

CHAPTER 3

METHODOLOGY

3.1   INTRODUCTION

"Basic research enhances fundamental knowledge about the world"

Neuman (1994:20)

Newman (1994) sees research as an essential ingredient in developing and furthering knowledge. This chapter describes the choices I made in undertaking such research. First, I explain my choice of qualitative research methodology and my reasons for choosing it. I then discuss my use of the interpretive approach, the case study method, purposive participant selection, the data collection instruments used, and method of analysis. Other important aspects such as ethical considerations and the reliability and validity of the study are also discussed.

3.2   AIMS OF THE STUDY

Durrheim and Wassenaar (1999:54) declare that the aims of research provide specifics with regard to the central area of investigation of the study. As noted by Bless and Higson-Smith (1995:42) a descriptive study aims to gain insight or enhance knowledge of a situation.

In order to support the siblings, an understanding of their life experiences is necessary. The aim of this interpretive study was to explore aspects of the lived experiences of siblings who have a sibling with a disability. These experiences include relationships with their siblings, roles and relationships within the family and among friends and peers, effects on their lifestyle, and sources of stress and the related coping strategies that are used.

This study aimed primarily to explore or discover what these siblings are actually experiencing. Secondly, it aimed to determine what siblings experience as positive and negative aspects of their lives in relation to having a sibling with a disability. It is

hoped that the findings will be useful in future studies and in the development of support interventions for the sibling as well as the family.

3.3   QUALITATIVE RESEARCH

This study adopts a qualitative approach. Qualitative research has a range of definitions but is described broadly by Denzin and Lincoln (2003:4) as "a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible". In this study I consider the world of the sibling of an individual with a disability as described in their words.

Despite the ongoing debate about the rigour and validity of qualitative versus quantitative research, it was the differences in the 'product', or 'data', of these types of research that led me to select a qualitative approach. Qualitative research takes place in natural environments and endeavours to make sense of the meanings that people ascribe to events or phenomena (Mertens, 1998:160)

The depth that qualitative research offered to this study was invaluable. This deliberate choice is backed up by the following aspects that qualitative research entails, as mentioned in Mason (2002:3):

- An interest in how the world is experienced and understood, the many layers of and meanings of the social world,

- Methods of data collection that are accommodating and aware of the social context,

- Methods of analysis that provide thick, rich descriptive data.

The qualitative approach was appropriate for this study as the participants in this situation were able to use their words to express and describe their life experiences. In this study, semi-structured interviews and open-ended questions were used to elicit accounts of the participant's reality or their lived experience in their own words.

3.3.1   Theoretical framework

This study assumes an interpretive research approach, as discussed in Chapter One. Merriam (2002:8) identifies these features of the basic interpretive study: the research endeavours to understand the meaning an individual makes of a situation or event; the researcher is a vehicle and mediator in gathering and interpreting data.

The resultant data are descriptive and inductive. A key feature of this paradigm is that the participant's reality is socially constructed and multiple realities can thus exist (Mertens, 1998:8).

Since this study was concerned with the experience as reported by the sibling of an individual with an intellectual disability, the semi-structured interview questionnaire aimed to elicit the feelings and daily life experiences that a participant might have when their sister or brother has a disability. The research goal was to access and to 'hear' the participant's personal experience in their own words, i.e. what these participants perceive as the difficulties or strengths that they live with each day. The intent was to determine whether there is a need for support and, if so, what the main aspects of the support should be.

However, as Willig points out (2001:53), the Interpretive Phenomenological Approach (IPA) does recognise that the experience of the participant is never directly available to the researcher, thus the researcher's world view, as well as the effects of interaction with the participant, is not discounted. The result is that the final analysis is an 'interpretation of the participant's experience' (Willig, 2001:53).

Mason (2002:76) states that a challenge to this approach lies in ensuring the researcher does not misinterpret or incorrectly interpret a participant's view or observation. Interpretive skills enable the meanings of words and feelings to be delved into and explored. It goes without saying that the influence of the interpreter's life, background, knowledge, etc. inherently affects these interpretations (Danaher & Briod, 2005:224). This 'bias' that may affect a research study is discussed later under 'The influence of the Researcher'.

3.4   RESEARCH DESIGN

The research design has two meanings according to Bless and Higson-Smith (1995:63). Firstly, it can be seen as the step-by-step plan of the scientific research. In this way it guides the researcher in the collection, analyzing and interpretation of the data. Secondly, it can be seen as the conditions and provisions that, when implemented, most accurately test a hypothesis. This study adopted the approach that the research design is a plan and guide for the researcher to follow to achieve the optimal value from the study.

Curiosity of the researcher or passion for a subject is perhaps the initial seed of a research study. Janesick (2003:51) discusses one of the decisive preliminary questions the researcher must ask in order to guide the direction and type of study, namely, what is it that I want to find out in this study? The answers to this question guide the methods and techniques that will be used throughout the study and thus this question must be carefully considered. These steps, the methods and techniques, provide a framework for the overall research design. These methods are elaborated on in the sections below.

This study is a descriptive study in that it aims at obtaining descriptions of life experience from the sibling of a child who has an intellectual or other disability. The individual's own actions, words and personal accounts or description of a situation are the primary data I sought to obtain. Exploratory research and descriptive research have many similarities. However, the main difference is found in the point of reference of the researcher of descriptive research. As Neuman (1994:19) states, the research commences with a specific and known topic, and the subsequent research endeavours to provide additional relevant description and detail.

The research design process and plan for this study is further described and discussed in the methodology and succeeding sub sections.

3.5   METHODOLOGY

Mason (2002:59) sees the researcher as having to identify the means of obtaining the necessary information, or data. The methodology of a study is what guides the researcher in the collection of data.

3.5.1   Case study

Case studies are a common choice in qualitative methodology. It should be noted, however, that there is debate on whether case study defines a method of research or the research design (Mertens, 1998:166). The implementation of a case study approach is often steered by the decision of what is being researched. Once the decision to do a case study has been made, the methods used to study the case or cases identified, can be chosen (Stake, 2003:134). In this study, the interview method was used to collect data.

Stake (2003:156) considers the case study useful in its broadening of our understanding and knowledge. He identifies three types of case studies. These are the intrinsic, the instrumental and the collective case study. The intrinsic case study is undertaken to provide the researcher with additional understanding of a specific case. The Instrumental case study looks at the case with the goal of furthering information regarding a certain issue, theory or phenomenon. The present study is classified as a collective case study. The collective case study is an extension of an instrumental case study, but it involves several cases, rather than just one case study. Smith notes that a case study assumes a bounded system. A bounded system exists since the study takes place at a specified time and place, and the cases studied are comprised of individuals who fulfil certain criteria (Smith, 1978 as cited in Merriam, 2002:178). Thus, in the case of multiple, or collective case studies, there are defined confines into which the cases fall. Four separate cases were explored in this study, that is, four siblings from different families were interviewed regarding their experiences when their brother or sister has a disability.

3.5.2   Participant selection

Flick (1998:73) describes sampling strategies as the means of defining a field of study. The sampling strategy or the process of selecting participants is defined by Mason (2002:120) as the process whereby the researcher defines and gains access to the data source, namely the participants, from which information will be generated using the chosen method.

The method of participant selection used in this study was that of purposive sampling, also named judgmental sampling by Bless and Higson-Smith (1995:95). Specific groups or individuals are selected according to their relevance to the research. Mason (2002:124) explains that they are judged to meet the criteria necessary to make the research study possible. As Mertens (1998:272) points out, the sample aims to represent variety. However, aspects such as accessibility of participants and time restrictions may affect sampling decisions.

As Smith and Eatough (2006:329) explain, the interpretative phenomenological approach (IPA) aims for a homogenous population. A specific and limited population group of siblings was available for the participant selection in this study. Additionally, the criteria for participant selection, as indicated below, were explicit and particular.

3.5.3   Inclusion and exclusion criteria applicable to participants in this study:

- A brother or sister of the participant must have been diagnosed with an intellectual disability, or a disability which includes a degree of intellectual impairment.

- The participant must be between the ages of eight and sixteen.

- The participant lives within a family context, i.e. they have lived or live at present as a member of their family.

- The participant sibling involved in the research has not been identified with any developmental disorder or disability.

- This participant sibling attends a mainstream school, with or without their sibling with a disability.

This type of purposive sampling aims to select participants who are described by Henning, van Rensburg and Smit (2004:71) as desirable for the study. While this theoretical sampling enables a 'delimited' population to be accessed, it must be mentioned that this may limit later generalisability to the population at large. However, well documented results and findings, and careful use thereof, may be conveyed to other situations (Henning et al., 2004:71). See further discussion regarding Transferability.

The researcher's judgment is used to define and select individuals for the study. This can be considered as a weakness as the researcher's subjectivity is used in selection. However, in a study in which the population is specific, but small or inaccessible, this kind of sampling is acceptable.

3.5.4   Participant details

Four families identified from a defined, limited population were contacted. These families were identified through personal and professional contacts of the researcher. The selected parents/ legal guardians were contacted via telephone and asked whether they would be prepared to allow their child to participate in this study. Had any family declined at this stage, another participant would have been contacted.

Table 3.1:   Participant information

Participant sibling. Participant's are coded and ages are grouped for anonymity	Family composition and Living arrangements	Participant older or younger than sibling with disability	Gender of sibling with disability
Participant 1 (P1) 8-10 years	Family A: 3 children. Child with disability and sibling living at home.	Younger	Female
Participant 2 (P2) 14-16 years	Family B: 3 children. Child with disability not living at home, sibling living at home.	Younger	Female
Participant 3 (P3) 8-10 years	Family C: 2 children. Child with disability and sibling living at home.	Younger	Male
Participant 4 (P4) 14-16 years	Family D: 3 children. Child with disability living at home, sibling at home on weekends.	Younger	Male

3.5.5   Data collection

Terre Blanche and Kelly (1999:128) have reservations about the term data collection. They state that the term can imply discrete information that is not necessarily context specific, whereas interpretive research works with material that is thick, rich and interconnected in its meaning. In this study the word data collection is used to refer to any information obtained via interviews, observations and reports. It does not signify the depth, or lack thereof, of the meaning of obtained information.

3.5.6   Collateral information

In this qualitative study, the instrument to gather information is the researcher (Durrheim, 1999). During the initial contact, which was made telephonically, an informal meeting was arranged, where possible, to meet the participant, parent or family. The meeting was designed to allow me to meet the participant and establish some familiarity in order to reduce anxiety in the subsequent interview. Where it was not possible to arrange such a meeting, telephonic conversations and a brief meeting before the interview had to suffice. The discussion during the contact

meeting or telephonic communication with the family, or parent, provided an opportunity to give general information about the study as well as for any questions they had to be posed and answered. The parents and participant were asked to sign an authorisation form confirming that they were willing for their child to be a part of this study, as well as the participant's consent to being part of the study. A parent was requested to complete a set of structured personal forms, anamneses, regarding the participant (See Anamneses: appendix 4-7). These questionnaires provided additional personal historical, demographic, developmental and psychological background information about the participant and family.

3.5.7   Review of literature

The literature review contextualises the current study and guides the study in confirming or building upon former studies. The review is related to specific topics, all of which are relevant to the current study. The review also guides the researcher in the identifying of a theoretical framework and methodologies that may be most constructive and practical (Kaniki, 1999:17).

A review of literature related to the subjects of disability, sibling experiences with disability and illness, disability in families, relationships among siblings, stress in families and coping, provided findings and opinions regarding related and similar topics.

A methodological review provided insight into the designs and paradigms that were suited to this qualitative study and the adoption of an interpretive framework.

3.5.8   The semi-structured interview

Terre Blanche and Kelly (1999:128) regard interviewing participants as an appropriate method for the interpretive paradigm. According to Bless and Higson-Smith (1995:105), the method most commonly used to gain information is through asking respondents directly. In this study, the semi-structured interview was chosen. This method uses a guide for asking questions but is less prescriptive and controlled than the structured interview. Mason (2002:67) describes the semi-structured interview as an intentional conversation, in other words a dialogue with intent. It allows the respondents the freedom to select their own words and descriptions that

communicate their observations and interpretations (Bless & Higson-Smith, 1995:107).

The advantages of the semi-structured interview lie in the richness and detail of data obtained, as well as the unearthing of new features of a situation or issue and possible further investigation of it during the interview. However the challenge lies in obtaining detail and depth of information. This is largely dependent on the skills of the interviewer and the nature of the relationship between interviewer and interviewee (Bless & Higson-Smith, 1995:110).

In the semi-structured interview, as described by Smith and Eatough (2006:331), the interviewer starts with broad questions in the hope that this will lead the participant to provide detail. Open questions can assist in putting the participant at ease, while if necessary; prompting can assist in gaining more detail in a certain area and moving from the general to the particular. The sequence of questions is less important than the researcher assessing when to ask certain questions and when to delve for more detail. The interviewer may well find that he or she was following avenues of inquiry that had not been planned in the interview schedule.

The interview process in this study consisted of one interview. Interview schedule questions were drawn up using the questions used in a previous study on sibling experience conducted in the United Kingdom. Permission was obtained from the researcher of this prior study to use this questionnaire as a basis (see Appendix 1). The duration of this interview was flexible, and dependent on how conversational, open and verbally expressive the participant was. See Appendix 3 for an outline of the semi-structured interview schedule.

All participant interviews were audio-taped and later transcribed to assure accuracy and validity. Reflections and observations made by the interviewer during the interviewing process were noted in brackets. During interviewing non-verbal cues and expressions are just as important as the actual words used. Mason (2002:77) suggests that not only a full transcription of all interviews be kept, but also that a record of observations and reflections be noted by the interviewer during the interview. See Appendix 9 for an example of a transcription of the interview with a participant.

3.5.9   Protocol for interviewing children

Breakwell (2006:244) suggests some of the ethical considerations that are necessary when interviewing children. Since the child was often not the party to consent to the study initially, each of the families was explicitly told that the parent or child had the right to withdraw from the study at any stage.

The issue of "acquiescence response bias" can lead to a child giving what they believe to be expected or socially acceptable responses. Attempts to avoid these responses are set up through the questions asked. Avoiding questions that allow for 'yes' or 'no' responses, and require more open answers can assist in this. Time and concentration must also be considered with young children. Interview must be kept concise and the interviewer must monitor the pace and questions or topics to assist in holding a child's attention. The location for holding the interview can also assist the interview process by being in a quiet place, where there is little activity and thus less distractible influences (Breakwell, 2006:245).

Wherever possible interviews were conducted in favourable environments. The interview used in this study was not lengthy; it consisted of ten questions. It was semi-structured, so I was able to go into further detail when the situation or response necessitated and allowed for it.

3.5.10   Observation

Merriam (2002:13) identifies observation as a major source of traditional qualitative data collection and describes it as a direct account rather than an indirect version or account. In this study, observation was used in conjunction with the interview to provide additional qualitative data to assist analysis as well as to strengthen validity. Researcher observations were made throughout the process of data collection. Notes were made regarding selection, initial contact, and telephonic contact or meetings, interview and post interview reflection. These observations were recorded and referred to during data analysis of interviews as well as the literature review. Observation, as mentioned by Mertens (1998:182) enhances credibility, or external validity.

3.5.11 Data trail

An updated list, or log, of all contact made with participants was kept during the data collection process; dates, details of contact and brief personal reflections were regularly noted and updated on this table. This data trail allows the study to be replicated in future research. It can also assist in backing up validity claims (Richards, 2005:43). The data trail, also named the audit trail, can demonstrate that your data were carefully collected using methodical and suitable means (Merriam, 2002:141). See Appendix 8.

3.5.12 Data analysis

In interpretative research the researcher is the instrument to mediate meaning (Merriam, 2002:6). According to Danaher and Briod (2005:218), the aim of the qualitative researcher is not to discover reasons and theories to explain a particular behaviour or feeling. Rather, the aim is to elicit themes and unearth their deeper meanings for the individual in a certain situation. Through this we hope to gain insight into a participant's experience. Garner (1991:140) argues that the aim of analyzing data is to uncover and elaborate what we consider to be essential significance in the raw data; to rearrange and assimilate information so that the readers can access the findings in an effective, appealing manner.

IPA influences the analysis of data in that it aims to explore the personal experiences of the individual and how they make sense of these experiences (Smith & Eatough, 2006:324). Smith and Eatough (2006:332) mention the difficulties and concerns that the novice qualitative researcher may experience. To overcome this they suggest absorbing and engrossing oneself' in the data. In a sense, this involves standing in the shoes of the participant, since you attempt to make sense of the data through the eyes of the participant as well as that of the psychological researcher. Analysis in IPA according to Willig (2001:54) involves moving from the initial frequent reading of text and developing general notes and comments, to further, deeper identification of themes. These themes provide the essence of what is being expressed by participants. Themes of similar nature can be grouped into clusters that describe the nature of the included themes.

The data were analysed using a thematic analytic process. This method, as Breakwell (2006:270) describes, aims to look at the similarities and disparities

between participants' reports to discover and uncover congruent and outlying experiences, both of which provide insight and information. Terre Blanche and Kelly (1999:141) provide a detailed description of the analysis process stages or steps. These five stages entail:

- Familiarising and immersion is the task of getting to know the material in detail through re-reading and transcribing data.

- Inducing themes is described as a bottom-up approach in which themes arise from the material. Categories arise from the ongoing re-reading of transcriptions and noting commonalities and differences. The actual words of the participants were thus repeatedly read to reveal deeper, abstract and more complex implications of their words.

- Coding is the third step. Coding commenced during the establishment of themes. Coding distinguishes the actual data in ways that are relevant to the study. Themes were named and detailed at this stage.

- Elaboration consists of the subtle exploration of differences within the themes established above. The categories are afforded detail and richness through discovering patterns and consistencies as well as exceptions and incongruence.

- Lastly, interpretation and checking is the final step. This process involves reporting on the themes as well as noting the personal impact of the researcher on the data. Personal influences were noted and mentioned in the interpretation stage.

The implementation of these steps of analysis is described in Chapter Four. Clustering, as mentioned by Willig (2001:55), allows further structure to be introduced into the analysis and provides links between themes by creating categories or 'clusters' of themes. These phases of analysis enable the process of analyzing data to be broken down into manageable steps.

Quotes and phrases can assist in clarification of the nature or naming of thematic categories. A visual display of data can be depicted through the dendrogram method, as discussed by Miles and Huberman (1994:250). The dendrogram demonstrates the increasing levels of abstraction in the analysis of themes. The data are depicted in this way in Chapter Four.

3.6 ETHICAL CONSIDERATIONS

Henning et al (2004:74) underline the researcher's responsibility for ensuring that ethical standards are maintained during the study. A study has to be conducted in an ethical manner in order to qualify as a good qualitative study since ethical considerations or the ethics of the researcher can affect the reliability and validity of the study (Merriam, 2002:29).

3.6.1 The ethical considerations and practices of this study

Basic principles listed by Barret (2006:39) were applied:

- Informing the participants and others involved in the study, such as families, regarding aims of the study and general procedure and what time sacrifices would affect them. All participants and guardians of participants were fully and openly informed about the study, via e-mail and telephonic discussion, before agreeing to take part.

- Assuring anonymity of all participants, and families. All names were changed in the reporting of results and pseudonyms or codes (Family A, Family B, P1, P2, etc.) were used. Any identifying data were disguised in this way to assure confidentiality.

- Obtaining informed consent from all participants and parents. A detailed consent form was provided to the parent or legal guardian as well as the participant. Both were requested to sign consent for participation in the study. This consent form allowed either the parent or the participant the right to refusal, and thus permitted them to be able to withdraw from the study at any stage. It was possible to make contact with the researcher telephonically had any party wished to withdraw.

- Upholding the principles of no deception and full transparency in all respects of this study. All information given regarding the study and procedures, as well as interview questions, was open and clear in its intention.

- Ensuring that participants have access to information regarding the study. Any participant that requested further information or feedback after the study was afforded the opportunity for discussion about the study itself or findings.

3.7   RELIABILITY AND VALIDITY

In this study, certain measures were taken to enhance the reliability and validity of the study. The data trail (see Appendix 8) detailed all contact with participants as well as my remarks and notes regarding contact and the results thereof. Notes, reflections and observations were made throughout the study and during interviews. These annotations allowed me to take into account the participants' body language and their unspoken communications during our meetings. An awareness of my effects on the study and my choice of approach to the study, as well as a thorough and careful analysis of data, were designed to augment reliability and validity.

3.7.1   Dependability

Dependability can also be termed reliability. According to Durrheim and Wassenaar (1999:64) the dependability of an interpretive study is the extent to which the findings are presented as reported. This is achieved through thick and comprehensive accounts obtained from participants (Durrheim & Wassenaar, 1999:64). Mertens (1998:184) states that a reliable study when replicated will present consistent findings. While Bless and Higson-Smith (1995:130) report that qualitative methods tend to be viewed as less reliable in rendering constant results with each study, Smith and Eatough (2006:329) argue that the strength of IPA is determined not by the uniformity or regularity of results, but rather by the new understandings and awareness it provides to the research question or topic.

3.7.2   Transferability

The ability to which the findings of a study can be used in another context, affects the transferability, or external validity. The depth of description and detail given can aid the criteria of transferability. Multiple case studies can also further improve transferability (Mertens, 1998:183). In this study four case studies were undertaken. The details of each case, as well as observations from phone calls and meetings, and the depth of description on the individual case situations can enhance transferability to other contexts.

3.7.3 Credibility

Credibility, also known as internal validity, looks at whether the participants' responses, their constructs, are aptly understood and portrayed by the researcher

(Mertens, 1998:181). According to Danaher and Briod (2005:224), the interpretative approach aims to further our capacity for understanding another's experience. Criteria that increase validity can be found within the descriptions of interpretative descriptions. Writings that have depth, intensity, simplicity, descriptiveness, and truthfulness, aid in guaranteeing validity (Danaher & Briod, 2005:225).

Enhancing credibility can be done via triangulation. In qualitative research, triangulation entails obtaining data from varying sources and checking for corroboration of inferences (Mertens, 1998:180). In this study parental discussions and observations as well as completed questionnaires were used to reinforce interview data. The literature review, presented in Chapter 2, of numerous journal articles, books and personal accounts was a means of supporting findings and avoiding making incorrect assumptions about the data.

3.7.4   Influence of the researcher

As Valle and King (1978:55) point out, our preconceptions and approaches in any undertaking will affect our involvement in it. What we consider as meaningful in research will influence the way we set about researching a subject or issue.

The impact of the researcher on the study must not be excluded or discounted. Background, values, ideals, goals etc., will all affect the process of the research project, as well as the interpretation and reporting of the data. In any study involving contact with an individual, the researcher therefore has an effect on the individual's experiences (O'Connor & Ammen, 1997:3). Personal reflection and observations on themes and interpretations opens up the analysis process and allows the researcher's own influence to be noted and taken into account.

3.8   CONCLUSION

This chapter justified described the theoretical and methodological approach used in this study. The methodology section discussed the techniques and practices used in carrying out the research from the initial selection of participants to gathering and analyzing the data. Crucial aspects of any study such as ethical considerations, reliability and validity were also addressed in this chapter.

CHAPTER 4

IMPLEMENTATION AND FINDINGS

4.1 INTRODUCTION

This chapter provides a detailed description of the implementation and findings of the study. While Chapter Three looked at the design of the research and the methods and techniques used for obtaining data, this chapter describes the actual execution of the study and the outcomes. It also discusses the data obtained, the analysis and interpretation of the data and the findings obtained.

4.2 IMPLEMENTATION

4.2.1 The case studies and context

Four participants took part in this study. Participant one (P1) was between 8 and 10 years of age. There were three children in this family. This participant's sibling with a disability was an older sister. The family lived together at home, but the two siblings referred to in this study attended different schools.

Participant two (P2) was between 14 and 16 years of age. There were three children in this family, one of which was a sibling from a previous marriage who lived abroad. This participant lived at home but her older sibling with a disability had recently started living in a facility where she was able to be more independent.

Participant three (P3) was between 8 and 10 years of age. There were only two siblings in this family. The sibling in the study was only minimally younger than the sibling with a disability. Both siblings lived at home and attended different schools.

Participant four (P4) was between 14 and 16 years of age. There were three children in this family. As in the other cases, this participant was the younger sibling. This sibling was at boarding school but lived with the family at weekends. The sibling with a disability lived at home.

4.2.2 Participant selection

As mentioned, participants were identified and selected according to a purposive or judgmental sampling approach. The names and contact details of possible participants were obtained through personal contacts and private means. The following table provides relevant participant details. Further participant information is discussed under Data collection.

Table 4.1:   Participant information

Participants are coded and ages are grouped for anonymity. Participant gender	Family composition and Living arrangements.	Participant older or younger than sibling with disability	Gender of sibling with disability
Participant 1 (P1) 8-10 years Male	Family A: 3 children. Child with disability and sibling living at home.	Younger	Female
Participant 2 (P2) 14-16 years Female	Family B: 3 children. Child with disability not living at home, sibling living at home.	Younger	Female
Participant 3 (P3) 8-10 years Male	Family C: 2 children. Child with disability and sibling living at home.	Younger	Male
Participant 4 (P4) 14-16 years Male	Family D: 3 children. Child with disability living at home, sibling at home on weekends.	Younger	Male

4.2.3 Data collection

The following techniques of data collection were used.

4.2.4 Relevant Participant information (from anamneses)

The anamneses forms that had been completed by a parent provided information about each participant's background, development and personality, as well as concerns or issues that may have been identified in certain areas such as developmental milestones, difficulties when attending school or accepting discipline

etc. This information was used in conjunction with the literature review as well as the observation to triangulate and thus enhance the credibility of the data.

See Table 4.2 for additional participant information. See appendices 4 to 7 for examples of the anamnesis.

Table 4.2:   Additional participant information

Parti-cipant	Personality and temperament	Sociability	Discipline	Concerns
P1	Independent, untidy, enthusiastic, active, easily distracted, loving, a leader, sympathetic, helpful, average self confidence, tense	Friendly and sociable, with average imaginative play.	Accepts discipline at home with difficulty at times. Has experienced fluctuating attitude towards teachers - related to anxiety and embarrassment.	"High anxiety" - worries about world events. When younger difficulty separating from mother when going to school.
P2	Independent, easy to manage, active, leader, enthusiastic, spontaneous, sympathetic, helpful, loving honest, cheerful, untidy, attentive, responsible, self-controlled, a great child.	Friendly and sociable, imaginative.	Accepts well.	None mentioned
P3	This parent was frequently contacted requesting the completed anamneses, but unfortunately had not yet completed these forms by the time this study was completed. This is a limitation in this study (see Chapter Five).			
P4	Exceptionally tidy, focussed, independent, easy to manage, active, leader, responsible, spontaneous, helpful, honest, cheerful, loving.	Friendly and sociable, imaginative.	Accepts well.	None mentioned

4.2.5 Contact with the family

In this study I made initial contact with the families telephonically and gave them a basic outline of the study, its purpose, and the requirements. If at this point the parent agreed to the study, further plans were made to meet the family. Two families requested that I send an e-mail giving them more information about the study. This was duly done, see Appendix 11. The parents of the two adolescent participants were inclined to allow direct contact with the participant to organise the interview. One parent said that the participant would have the sole power to decide whether to agree to the interview. Fortunately the participant did agree to be interviewed.

An informal meeting had been planned to meet the child, parent or family, before the interview where possible. However, this meeting did not take place with the majority of the families because of factors such as time constraints, work responsibilities and other plans. It was either cancelled or could not be scheduled in the first place. The disadvantages of not having this meeting are noted in Chapter 5 under limitations. This initial meeting was useful in two ways. First, it allowed the family and participant to meet me and thus provided an element of familiarity before the interview. Secondly, it provided additional information and observational data for the study. In cases where a meeting could not be held, I had to be content with telephonic conversations to gain additional information.

At the time of the interviews a parent and participant were asked to sign an authorisation form acknowledging that they had agreed to participate in this study (see Appendix 2).

4.2.6 The semi-structured interview

The primary tool of data collection was that of the semi-structured interview. An interview schedule was used to guide the questions (see Appendix 3). The semi-structured nature of the interview allowed for elaboration or digression into matters not mentioned on the questionnaire schedule. I amended the interview schedule after the first interview to make it easier to use and to obtain more data. This entailed adding questions to introduce and open up various areas of enquiry. These questions are displayed in italics on the original questionnaire (see Appendix 3).

The semi-structured interviews with the adolescent participants lasted between 45 and 60 minutes. The interviews of the younger participants did not last as long, ranging between 25 and 30 minutes. The young age of two of the participants at times required that I explain certain terms and modify certain questions without changing the meaning or leading the participant. This is discussed in Chapter Five under Limitations. All interviews were transcribed for later analysis. See Appendix 9 for an example of transcription.

4.2.7 Observation

I used observation as a supplementary tool, primarily during the interview with the participant, and additionally during any contact with the families. During our meetings I noted the participant's body language, intonation and other non-verbal cues while he or she was talking about a certain event or experience. These gave additional information about the participant's experiences.

Observations during meetings with the family, as well as telephonic conversations, were used to assist in providing additional information to verify my understanding and interpretation of situations and conditions experienced by the siblings in the family (See Appendix 12).

4.2.8 Data trail

The data trail documented all contact made between myself and participants or families. This gives the dates, the types of contact made, the duration of contact, and comments relating to the contact. This trail provides an audit of when and how the actual implementation of the study progressed and provides information regarding planning, timing and activities for future studies. See Appendix 8 for the data trail.

The literature review in Chapter 2 provided a great deal of information regarding previous studies and findings related to experiences of siblings and families of a child with a disability.

4.2.9 Ethical considerations

Ethical principles, as discussed in Chapter Three, were ensured throughout the study. Some parents requested an e-mail giving details about the study, which I sent to them. In all cases I carefully discussed the study, its confidential nature, as well as the study details on the consent form with each participant before the interview. Any

questions were answered. After this discussion, the participant signed the form. Participants and families were offered the opportunity for feedback on the findings of the study at their request. However, no requests were made.

4.2.10 Reliability and validity

- *Dependability*

To ensure the reliability of this study, care was taken to describe in detail how the data were collected and analysed, and observations were noted throughout the study. A data trail was maintained. This audit of all contact with families or participants and the progress of meetings, interviews and other documentation allow the progress of the study to be followed (see Appendix 8).

- *Transferability*

The use of four unrelated case studies, as well as information obtained from parents, observations and descriptions of the participants and their family situation makes it possible for the findings from this study to be transferred to similar contexts.

- *Credibility*

Triangulation enhanced the credibility of this study. This involved exploring other information provided by the parents, observations and the literature review to provide backing for interpretations and findings made from the primary data source, the interview.

4.3 DATA ANALYSIS

4.3.1 Thematic analysis

Transcripts of the interviews were analysed using thematic analysis. Stages of analysis as supported by Terre Blanche and Kelly (1999:141) were described in Chapter Three. The five steps they described were implemented as follows:

1. All interviews were recorded and transcribed and observations were noted. All transcripts were read numerous times and notes, comments and questions documented on the transcripts. In this way I was able to familiarise myself with the data. During this reiterative reading of transcripts, I attempted to recall the

interview situation as afresh and read the transcript with as little reference as possible to my previous thoughts or notes on possible themes.

2. Themes emerged from the material. The concrete world of the participant evolved into categories which reflected the abstract more complex implications of the material. From the respondents' words and stories, regular issues and subjects emerged. While rereading transcripts and notes these 'emerging themes' were recorded, as is discussed in the process of coding, below. I found it challenging to maintain a 'clean slate' and avoid naming 'trends' in themes. However, in all cases I endeavoured to use a description that I felt reflected the participant's expressed sentiment or experience most closely.

3. Coding progressed during the development of themes. During the above stage of establishing themes, common and unique words, topics and issues were noted from the text of each transcript as well as from my notes and observations. From each transcript I extracted a list of themes. Thereafter, descriptive theme headings were applied to categorise and organise these first order themes or topics from the separate transcripts. Line numbers were used to identify where themes had originated, should I need to confirm my coding. Thereafter, I developed a combined document of the themes from all four transcripts, and the themes central to all participants became more apparent.

4. Exploration of differences within and between the themes and elaboration of themes occurred next. The core themes that were established from the previous steps were carefully examined in conjunction with observations, reflections and notes. This allowed for further deliberation of certain responses, and thus more in-depth consideration of categories and naming of specific themes. This process was very demanding. Deliberating on the meanings and nuances of words, in conjunction with my observations, often necessitated that I carefully consider the implication of the participants' spoken, and unspoken, communication. This often meant that I had to re-read the interview transcripts several times to confirm or refute the coding of themes done in steps two and three above.

5. Finally interpretation was undertaken. Common as well as unique themes and accounts were reported. Findings and interpretations were carefully considered

in light of the nature of qualitative research, the context of the interviewee, as well as relevant literature. To the best of my ability I reflected on, and took into account personal influences that may have affected the interpretation of the material.

The above steps enabled and facilitated the analytic process of this study. Quotes from the data of words and phrases (with transcript and line numbers) provided support and rationalisation for the development of certain thematic categories. Reflecting on themes and interpretations helped to reveal my influence and thus to take it into account. This highlighted the ways in which the analysis and interpretation process can be influenced and the importance of taking this into account when considering the validity of findings.

4.3.2 Emergence of themes

As a result of using the process described above, certain themes emerged from the data. A separate analysis of each participant's transcript was conducted. Themes and supporting quotes derived from each transcript are detailed below. This is followed by a brief discussion of the central themes.

- **Participant 1**

Themes that emerged from participant's (P1) account:

Themes	Quote	Line numbers
Feeling annoyed	"I just felt, got annoyed"	135
Irritation	"ja, stuff like that, angry, irritated"	108
Acceptance	"I am happy with what I've got"; "No, I am happy with my life"	38; 157
Loved by sibling	"one of the best parts is probably that she loves me so much .. and she cares a lot about me"	27
Resignation/ passive acceptance	"I dunno, I just have to deal with it"; "I just say to myself 'well there is nothing I can do about it' "	51; 71
Differential treatment - higher expectations	"but my mom thinks I can do a lot better"; "they expect, they expect quite a lot, I think"; "sometimes and they just say 'deal with it'"	42; 57; 65

Themes	Quote	Line numbers
Understanding	"then they'll explain why … and … ja, um ja most of the time I really do [understand]"	67-69
Embarrassment	"oh yeah, um when she picks her feet in public"; "so I said 'ok, whatever'"	114, 129
Anger	"stuff like that, angry, irritated"	108
Uncertainty	"sometimes I don't know how to explain what she's got … so …"; "um, I don't know really … that's a hard question to answer"	123, 140
Avoidance	"so I said 'ok, whatever' '"; "I just have to deal with it"	129; 51
Trust in friendships	"no, 'cos I trust my friends"	139
Increased sensitivity	"hey guys …, she cant do anything about it, shut your trap' "	103
Increased independence	"I am allowed to go out with friends by myself, and stuff like that"	145
Responsibility to care/ protect	"she cant do anything about it, shut your trap' "	103

- **Participant 2**

Themes that emerged from participant's (P2) account:

Themes	Quote	Line numbers
Increased sensitivity	"if you are Captain obvious with her then you are then it will end up her being hurt."	196
Acceptance	"she's turned out ok" "I never judge" "open minded, not as judgemental"	14 351 358
Resignation/ passive acceptance	"they're all things you can live with. Obviously, life would be easier without them but, ... people have handled worse" "she doesn't actually listen to me so even if I tried to get involved she wouldn't" "It's like a wart, ... it grows on you"	202-203 177 136
Irritation	"she used to always repeat and repeat and repeat"	18

Themes	Quote	Line numbers
	"All she can ever talk about is [topic]. All she can ever watch is [program]"	21
	"I have to be the one who, while she isn't looking, takes things out of the basket"	181
	"oh that's another thing, every single morning I wake up to "meisie, meisie" "	376
Understanding/ tolerance	"[understanding] wasn't easy actually at first but, … It's like a wart, … it grows on you"	136
	"also I try to understand her whole 'soapy' thing"	124
Pity/ sympathy/ sadness	"so now we all know he's got a girlfriend … but now she thinks"	31
	"she know she cant do things, and I think its slowly killing her"	51
	"it's horrible to see how ... what she's going though"	55
	"she's the one suffering"	64
	"It's like a wart, … it grows on you"	136
Guilt	"It would be mean to say that I like it"	47
	"Not to get away from her or anything"	387
Relief of guilt	"I never did say anything like "oh you're retarded and blah blah blah"	43
	"'cos I don't think I could live with myself … if I remembered saying things like that"	44
Siblings self-sufficiency	"she moved out about half a year ago. She is in a place where they live and work"	35
Personal growth	"its like … helped me as a person"	50
	"I think I don't judge people"	361
	"more mature"	363
	"open minded"	358
Awareness	"I think it's made me a little more aware of things"	346
	"open minded, not as judgemental"	358
Conflicting feelings	"I am really glad she is here to teach me something but it's horrible to see how ... what she's going though"	54
	"I am happy she is here to help me develop as a person but she's the one suffering"	63

Themes	Quote	Line numbers
	"she doesn't understand, so it won't make any difference."	64
Frustration	"you can't really get the message through"	93 81
	"When I get frustrated I can't really let it out on her … I can't let it out on her 'cos she won't understand why."	
	"she doesn't understand, so it won't make any difference."	64
Different expectations	" [expectations] are not too high, but they are a little more than I think they would have been"	111
Different treatment	"[doing additional chores] happened a bit when I was smaller"	96
	"she's always shirking responsibilities"	98
	"I think the more siblings, the more the responsibilities are distributed, so its kind of like being an only child with the responsibilities"	112
	"[chores/ tasks] are spread out, so the more siblings the less it is each"	118
Different opportunities	"there is not much competition for anything … like a tradition to uphold or something they need to beat"	66-68
Sacrifice	"Because normally it's a give-give situation"	191
	"but we never miss anything of hers"	193
	"I have had to adapt my time management"	194
	"I can't eat certain things, she's not allowed sweets and … I have to hide it or put it away even though I really want it"	219-221
	"we have to adapt our whole holiday"	228
	"whenever there was a school thing mom dragged me to help out … stand with tin collections, made all the posters and everything"	121
Time management	"I have had to adapt my time management"	194
Increased sensitivity	the way I speak, I have to be careful what I say … 'cos I might hit a sensitive spot"	199
	"I think I think too much for my own good"	259

Themes	Quote	Line numbers
Trust in friendships	"They all accept my sister. They're very open minded"	283
Embarrassment	"only on family occasions"	205
Interacting relationship	"relationship is a good word, even though we are like not interacting … It's always good"	292
Future concerns	"I have wondered about what will happen and who will support her if something should happen to my parents and stuff"	266
	"she'd have to stay there the whole time she wouldn't be able to go anywhere, she wouldn't be able to have all her special things bought for her."	269-271

- **Participant 3**

Themes that emerged from participant's (P3) account:

Themes	Quote	Line numbers
Annoyance	"and he kind of annoys me"	21
Frustration and exasperation	"he always has to come and bat and then we can't, we don't get a chance and we get frustrated";	34
		27-29
	Interchange with brother: becomes irritated and frustrated during his attempts and runs his hands through his hair and throws his head back	
	"but it frustrates me"	69
	"… getting frustrated"	113
	"probably frustrated too, 'cos can't really take it anymore"	115
	"I dunno, it makes me feel frustrated …"	171
Embarrassment	"uh-uh. I don't tell anyone (shakes head, looks down)"	37
	Ever been embarrassed? "yes …"	118
'Bad' feelings - pity, fear	"I feel bad that he can't play cricket with us, because if I had a brother that was like normal I would have um … got to play with him"	53-55
	"it felt bad" "I don't wanna lose my brother"	104-106

Themes	Quote	Line numbers
Guilt	After saying he *had* felt embarrassed, P3 said: "Um not really, I haven't really been embarrassed by him"	121
Humour	"the best part is that he's so funny" "Sometimes they laugh when he's funny, 'cos sometimes he's SO funny …"	60 140
Pride	"sometimes he's SO funny … "	140
Caring, love, acceptance	"I really like him as a brother"	164
Anger	"he always, he ALWAYS, whenever he starts crying, he always has to PUNCH me somewhere"	64
Increased expectation	"makes me always have to go to different schools for sport, and I want to stay at my own school." "makes me do a lot of sport and I am so, so tired. I feel so tired sometimes. He makes me do Camps Bay soccer and he makes me do school soccer, and now he makes me go to different schools …"	78 85
Irritation	Friend came downstairs to tell him that (brother) wanted to watch movie. P3 was hassled by this, but he still attempted to help by providing a solution "I'm outside and he comes outside and asks me to put on a movie for him, it's quite irritating"	88 146
Concern (fear and uncertainty)	"he disappeared and we had to go and fetch him, we just found him" "I don't know, I don't wanna lose my brother"	101 106
Avoidance	"I don't tell them anything. I just keep it to myself" "I would just say 'its none of your business' "	133 139
Trust in friendships	"but I tell XXX 'cos he is one of my best friends."	133
Care giving role	"I have to take care of him, I have to look where ever he goes …" "asks me to put on a movie for him"	97 146

- **Participant 4**

Themes that emerged from participant's (P4) account:

Themes	Quote	Line numbers
Frustration	"I can get frustrated about that" (at stubbornness) "very stubborn" "stubborn, and that frustrates me" "I like found that quite frustrating 'cos I didn't like …"	19 17 98 216
Humour	"sometimes he can't act mature anymore and he will start laughing" P4 smiling about "acting mature"	31 35
Annoyance and Irritation	"very stubborn which annoys me" "And sometimes they can be irritating"	17 99
Perceive advantages	"[changes are] basically all positive" "I'm very lucky in that way … I know how to relate"	203 69-71
Realisation and awareness of difference	"I started realising that there was something that was different. But I suppose slowly as I grew up I started realising the repercussions of being Down syndrome" "so I think like after, when I had finished grade one I probably was above him"	40-42 61
Embarrassment	"the disadvantage I found is I, I got very embarrassed sometimes ... I was scared like people would tease me about him" "he has embarrassed me on a few occasions and I've got quite cross" "I'd rather not my friends see my brother 'cos I'd be, feel embarrassed"	73-75 102 218
The future	"he always says he's gonna get married and he's going to have children … I didn't know if he was allowed to have children, if it was legal. But then all my friends told me that all Down syndrome children are infertile"	48-51
Guilt	"I dunno, I just didn't want to … I, I didn't stand up for him 'cos I don't want to, people to tease me" "one of my team mates stood up for him …" "well then I used to find like I'd rather	78 228 218

	not my friends see my brother"	
	Hesitation and some anxiety in relating [embarrassing] event	238
	"I shouldn't have feel that embarrassed and that angry sometimes"	106
	"I feel guilty about maybe being embarrassed when I shouldn't have been … maybe that upset him a bit, that I felt embarrassed"	393-395
Anger/cross	"on a few occasions and I've got quite cross"	103
	"I shouldn't have felt that angry sometimes"	107
Different expectations	"[higher expectations] sometimes yes but generally not"	115
	"we have to help our parents, then he often doesn't, he just, he doesn't want to and he cant, he won't help"	116-118
	"'cos I'm doing all the work 'cos he's not"	119
Differential treatment (and punishment)	"me and my brother find that my parents don't give him enough punishment"	122
	"but beforehand I always found he was more spoilt, he always got, always what he wanted he normally got"	127-129
Care for and comfort each other	"if I was hurt or I was crying he would always um like come up to me and ask what's the matter"	143
	"I knew that he was um like understood what I was going through"	145
	"if something had happened to him at school or something upset him I would always try and comfort him"	146
	"I used to comfort him if there was something"	149
Care giver role	"but we would always look after him" ("babysitting")	154
	"ja, we knew we had to look after him."	157
Pride in siblings self-sufficiency	"he went to work there one day and it was closed … I mean, I don't know what I would have done"	278-280
	"he actually walked to the petrol station … and he asked if he could use the phone and … phoned his teacher and	286-289

	… he waited there for about an hour or two, patiently"	
	"he coped well. [He] is extremely independent. Very much more independent than anyone expected"	291
Recognition of achievement and ability	"he can score goals and everything"	164
	"in cricket I don't know if he's lucky of coordinated but he always seems to score a lot of runs"	166
Understanding/ tolerance	that's why I could understand that"	244
	"So it depends who I am speaking to"	318
	"maybe he's made us more understanding and tolerant"	390
Close friendships	"I normally invite only my really good friends home"	338
	"So I've never had problems with my friends and Down syndrome"	342
Personal growth/ maturity	"the embarrassing moments I had then actually aren't embarrassing anymore and they've actually helped me out"	223
	"I think all round the changes I've had to make because of him have been positive. And have helped me"	204
	"I knew he was like looking for attention and just trying to like jerk around"	233
	"that's why I could understand that"	244
	"more understanding and tolerant"	390
	"if he wasn't Down syndrome I think I would have been quite different as a person"	355
	"I feel that I've gained more and … I've got a more of an advantage than other people"	352
	"maybe not even as mature."	357
Empathy	"not embarrassed like personally, but *for* my friends"	347
Acceptance	"maybe not have accepted and [been] understanding"	356
	"once you've lived with your brother for 15years you don't wanna change him."	367
	"I think in a way we feel very lucky to have (brother) and very understanding"	389

Themes were identified from the transcripts of the interviews with participants. Links were then established between the themes that had emerged. The next step was to group the themes into relevant clusters (see Willig, 2001:55). These clusters are explored in the next section.

4.3.3 Main themes: Clusters

The following 11 clusters make logical groups from the random themes that emerged from each participant's accounts. Each main theme, or cluster, consists of groups of themes and concepts based directly on the words and topics in each participant's transcript. The participant's reference is recorded in brackets after each theme.

- Feelings of discontent and stress.

    - Frustration (P2, P3, P4)
    - Irritation (P1, P2, P3, P4)
    - Annoyance at stubbornness (P1, P3, P4)
    - Anger (P1, P3, P4)

- Feelings of embarrassment (P1, P2, P3, P4)

- Conflict feelings

    - Guilt (P2, P3, P4)
    - Feeling 'bad'/ pity (P2, P3)
    - Avoidance (P1, P3)
    - Resignation/ Passive acceptance (P1, P2)

- Feelings of anguish

    - Concern/ Pity (P2, P3)
    - Uncertainty (P1, P2)
    - Fear (P3)
    - Increased sensitivity (P1, P2)

- Feelings of sacrifice

    - Time (P2)
    - Adapting to siblings needs (P4, P2, P1)
    - Increased availability for sibling (P2)

- Protecting/ looking after (P1, P2, P3, P4)

- Experience of differential treatment

    - In punishment and tasks (P1, P2, P4)

    - In expectations (P1, P2, P3, P4)

- Experience of reciprocity in caring

    - Love (P1, P3, P4)

    - Comfort each other (P1, P4)

- Feelings of pride

    - In siblings ability (P4)

    - In siblings self-sufficiency and independence (P2, P4)

- Feelings of acceptance

    - Attachment with sibling as-they-are (P1, P2, P3, P4)

- Experience of personal growth

    - Maturity (P2, P4)

    - Increased awareness (P2, P4)

    - Increased opportunities and independence (P1, P2, P4)

    - Advantage through understanding and empathy (discussed above)(P2, P4)

- Experience of close, trusting friendships (P1, P2, P3, P4)

4.3.4 Discussion of theme clusters

The main clusters could be further grouped into two predominant categories, namely experiences of a difficult or stressful nature, and constructive experiences and positive feelings. The following discussion elaborates on the clusters of experiences established above.

4.3.5 Experiences of difficulty and anxiety

Participants reported a variety of concerns and difficulties. These experiences were expressed in a variety of ways, reflecting anxieties, fears, internal conflicts, frustrations etc. The experience of feelings of discontent and stress included feelings of frustration at a sibling's behaviour or interaction: "When I get frustrated I can't

really let it out on her … I can't let it out on her 'cos she won't understand why." (P2, line 81); "I dunno, it makes me feel frustrated …" (P3, line 171); "stubborn, and that frustrates me" (P4, line 98). Irritation was expressed at times and annoyance, specifically at a sibling's stubborn behaviour, or 'repetitive' and routine activities was a common experience: "he kind of annoys me", "asks me to put on a movie for him, it's quite irritating" (P3, line 21, 146); "she used to always repeat and repeat and repeat" (P2, line 108). Anger was also experienced: "stuff like angry, irritated", "I just felt, got annoyed" (P1, line 108, 135). This was often associated with the frustration referred to above, as well as internal conflict, which is discussed later. Feelings and experiences of being treated unequally may also cause frustration.

The experience of differential treatment was in certain instances associated with situations in which the sibling with a disability did not pull his or her weight: "we have to help our parents, then he often doesn't", "he always got, always what he wanted" (P4, line 116, 127); "additional chores] happened a bit when I was smaller" (P2, line 96). Consequently the participant frequently had to perform additional tasks. Participants reported awareness of difference in expectations, "but my mom thinks I can do a lot better", "they expect, they expect quite a lot, I think" (P1, line 42, 57); "makes me do a lot of sport and I am so, so tired" (P3 line, 85); "expectations] are not too high, but they are a little more than I think they would have been" (P2, line 111). Other types of differential treatment were described as the disparity in parental treatment when it came to issues such as discipline and associated punishment: "find that my parents don't give him enough punishment" (P4, line 122). Participants did mention other situations from which they benefit, thus perhaps perceiving the legitimacy of this differential treatment. The experience of sacrifice of one's time and effort may be associated with this differential treatment. A core aspect of the experience of sacrifice was the lack of reciprocity; this was experienced by one participant in particular. This participant mentions it is a "give-give situation" (P2, line 191) in which she had to constantly 'give'. The sibling with a disability was infrequently perceived as having to relinquish his or her activities or time for the sake of the other siblings: "we never miss anything of hers", "I have had to adapt my time management" (P2, line 193, 194). Caring for a sibling was at times viewed as a sacrifice in terms of own time and activities being affected. In one instance, the need to be consistently watchful over the sibling with a disability appeared to be

wearisome and thus sacrificial on behalf of the participant: "I have to look where ever he goes …" (P3, line 97). This introduces the aspect of experiences of concern or despondency that a sibling may be exposed to.

Concern for a sibling's well-being and fears for his or her safety caused experiences of distress: "it felt bad … I don't wanna lose my brother" (P3, line 104-106). Feeling bad or pitying a sibling increased sensitivity to a sibling's disability: "the way I speak, I have to be careful what I say … 'cos I might hit a sensitive spot" (P2, line 199); "feel bad that he can't play cricket with us, because if I had a brother that was like normal …" (P3, line 53). Uncertainty as to how to explain a sibling's disability to others appeared to be anxiety provoking: "sometimes I don't know how to explain what she's got … so …" (P1, line123). Feelings of embarrassment were a common experience, usually occurring when a sibling could not express or explain his or her brother or sister with a disability's unusual behaviour or demeanour. Differing degrees of embarrassment were mentioned by all participants: "oh yeah, um when she picks her feet in public" (P1, line 114); "uh-uh. I don't tell anyone (participant shakes head, looks down) (P3, line 37); "I got very embarrassed sometimes … I was scared like people would tease me about him", "he has embarrassed me on a few occasions and I've got quite cross" (P4, line 73-75, 102). In many cases their embarrassment was followed by guilt and remorse for this self-consciousness. These conflictual feelings are discussed next.

Conflicting feelings are those sentiments which may induce a discordant reaction or response. The experience of guilt was frequently mentioned: "I shouldn't have feel that embarrassed", "I feel guilty about maybe being embarrassed when I shouldn't have been … maybe that upset him a bit, that I felt embarrassed" (P4, line 106, 393-395). Accounts of irritation or embarrassment were regularly connected to accounts of feeling pity for, or 'bad for' ones sibling's situation, "I feel bad that he can't play cricket with us, because if I had a brother that was like normal I would have um … got to play with him" (P3, line 53-55). Other conflict feelings are reflected in statement such as "I am really glad she is here to teach me something but it's horrible to see how ... what she's going though (P2, line 54). It seemed that for participants these experiences relate to much grappling with the duality of certain experiences. Passivity may be a sibling's manner of dealing with situations that are

difficult to resolve and seem inevitable. Resignation and passive acceptance were reflected in the recognition of inability to change a situation: "they're all things you can live with. Obviously, life would be easier without them but, … people have handled worse", "It's like a wart, … it grows on you" (P2, line 202, 136); "I dunno, I just have to deal with it", "I just say to myself 'well there is nothing I can do about it'" (P1, line 51, 71). Avoidance was seen in the denial and, or, avoidance of embarrassment after acknowledging times of experiencing embarrassment: "Um not really, I haven't really been embarrassed by him", "I don't tell them anything. I just keep it to myself" (P3, line 121, 133).

The older participants' had considered future possibilities when their parents could no longer care for a child with a disability. They appeared willing to support or be available to help their siblings in the future. It seemed that they had readily accepted their future role and saw it as a given: "she's self sufficient. But obviously we will support her when my parents stop working, and that's, um … pretty obvious" (P2, line 246), "because we live on a farm I think he will always um be able, always some sort of home on our farm" (P4, line 268).

While all participants reported some degree of experience of difficulty and anxiety, they similarly all expressed many encouraging and beneficial experiences that were attributed directly to their experiences of having a brother or sister with a disability.

4.3.6 Constructive experiences and positive feelings

The experience of feeling loved and comforted by a sibling and in turn being there for their sibling indicated the reciprocal caring aspect of these sibling relationships: "one of the best parts is probably that she loves me so much" (P1, line 27); "relationship is a good word, even though we are like not interacting … It's always good" (P2 ,line 292); "I really like him as a brother" (P3, line 164); "if I was hurt or I was crying he would always um like come up to me and ask what's the matter" , "I used to comfort him if there was something" (P4, line 143, 149). Recognition of a sibling's ability was a component of the caring relationship these siblings shared. It was clear that they took great pride in their disabled siblings' coping skills and their ability to manage in situations on their own. One participant recounted a challenging situation and went as far as to say: "I mean, I don't know what *I* would have done" (P4, line 280), thus acknowledging his brother's ability to handle a particular challenge with apparent

ease. The two older participants' accounts of their sibling's self-sufficiency in their living arrangements and job-related situation signified their recognition that this independence was an achievement: "she moved out about half a year ago. She is in a place where they live and work" (P2, line 35); "he coped well. [He] is extremely independent" (P4, line 291). Admiration for specific traits, such as humour, were reported: "they laugh when he's funny, 'cos sometimes he's SO funny …" (P3, line 140) was said with an appreciative smile. An appreciation of and admiration for their sibling, regardless of their disability, was clearly evident, as discussed below.

Acceptance of a sibling 'as-they-are' was collectively noted with all participants in the "magic wand" question. This question asked a participant what they would change if they had a magic wand. No participant chose to change their siblings in terms of their disability: "Once you've lived with your brother for 15 years you don't wanna change him" (P4, line 367). Only one participant chose to enhance his sibling's ability in sport: "um, I would like to make my brother a very good soccer player … uh-uh, nothing [else] really, I really do, I really like him as a brother" (P3, line 160-163). It appeared that participants did not want to change their siblings to satisfy their own needs or for personal reasons. This learning to accept another unconditionally demonstrated an element of respect and maturity, as mentioned below.

The experience of personal growth included many aspects that I felt represented the participant's mature and confident understanding and awareness of their life. A main theme, often reflected by the participants themselves, was that of maturity and understanding: "I think all round the changes I've had to make because of him have been positive. And have helped me ...", "[I might have been] different as a person, not incredibly, but maybe not have accepted and understanding, and maybe not even as mature" (P4, line 204, 356-357); "more mature", "open minded" (P2, line 363, 358). Another aspect of personal growth was that of increased opportunities as there was less perceived rivalry: "there is not much competition for anything … like a tradition to uphold or something they need to beat" (P2, line 66). At times their greater independence was acknowledged: "I am allowed to go out with friends by myself, and stuff like that" (P1, line 145). Increased awareness, of others, was a common response indicating an ability to think about something from another's view: "[I'm] not as judgemental" (P2, line 358); "I'm very lucky in that way … I know how to

relate with them, and I know what to talk about and how to get on", "Not embarrassed like personally, but *for* my friends" (P4, line 71, 347). This awareness and understanding facilitated empathy, also evident in most participants. Some participants were able to convey the benefits and advantages of having lived with a sibling with a disability: "its like … helped me as a person" (P2, line 50) "I think all round the changes I've had to make because of him have been positive, and have helped me", "I see that it's a big advantage", "I've gained more … I've at a more, I've got a more of an advantage than other people" (P4, line 204, 210, 354). Participants' demonstrated a mature and respectful nature, apparent from their accounts as well as during interviews. This may account, in part, for the reports by all participants of having loyal and strong friendships to rely on. All participants strongly related to the experience of close, trusting friendships. The familiarity and security of faithful friends appeared to comprise a strong support element for all four participants: "'cos I trust my friends" (P1, line 139); "They all accept my sister. They're very open minded" (P2, line 283), "I tell XXX 'cos he is one of my best friends." (P3, line 133); "I've never had problems with my friends and Down syndrome" (P4, line 342).
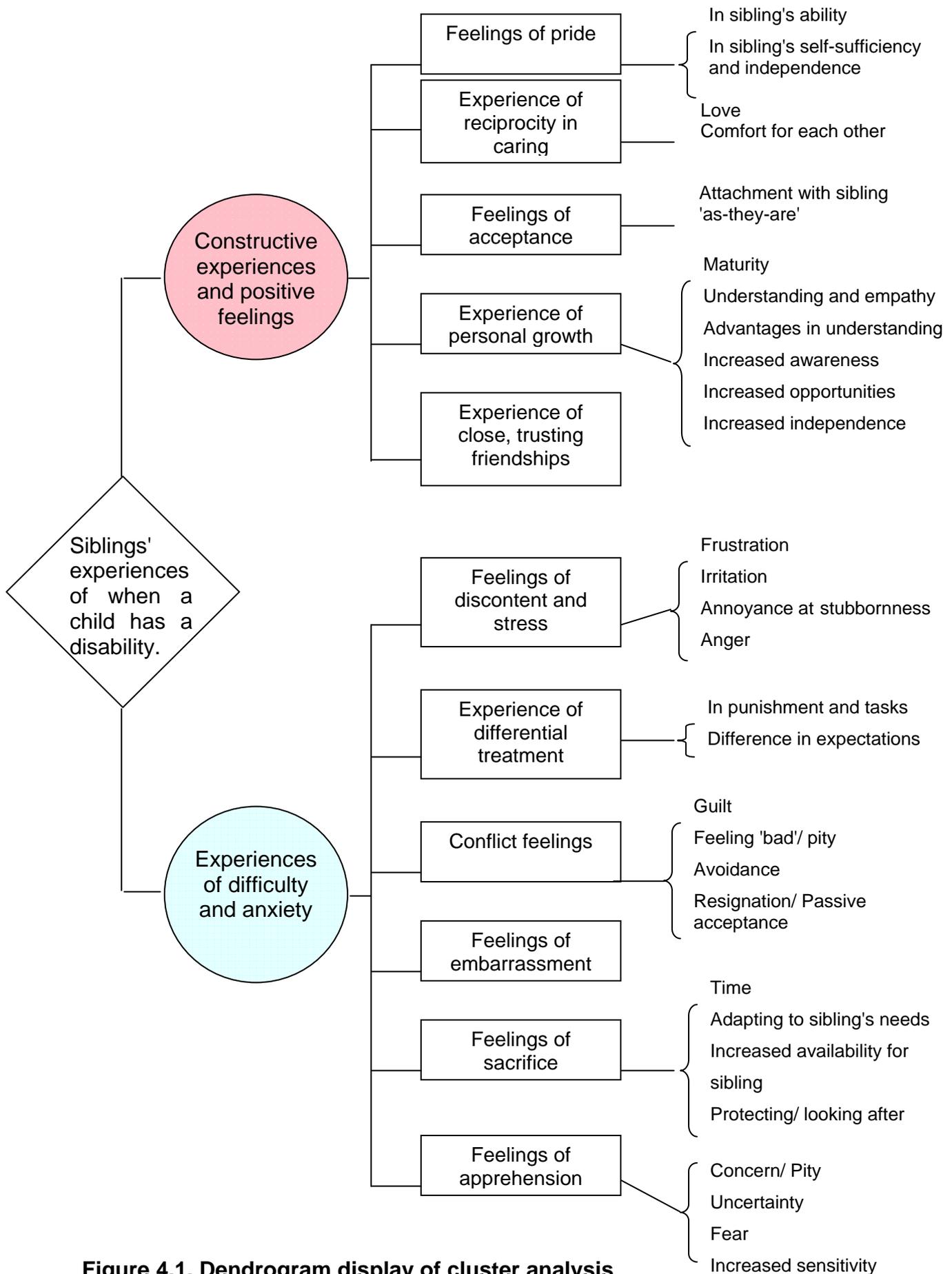
Figure 4.1. Dendrogram display of cluster analysis

4.3.7 Personal reflection on the analysis process

In the above analysis of data, each transcript was separately analysed and sometimes these analyses occurred weeks apart. I did all I could not to reflect on other participants' interviews or transcripts during my initial reading, the rereading, and coding of each transcript. I hoped this would help me to avoid having preconceptions about themes or topics. An indication of my success is that I frequently found that I had used different words to code or 'name' similar themes. In the next stage, I adapted and adopted certain theme names which clearly represented the common sentiment or fell within a thematic cluster. The iterative process of analysis thus allowed for the continual deepening and refinement of thematic clusters and the uncovering of the underlying central themes.

4.4 CONCLUSION

This chapter provided an in-depth description of the actual process and execution of this study. All of the stages of the study and its progress were carefully detailed. The outcomes were presented in the analysis of data and the dominant themes uncovered. In the next chapter, these findings will be related to the literature review. I will then reflect on the limitations of this study and suggest considerations that could be taken into account in future studies.

CHAPTER 5

DISCUSSION OF FINDINGS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

In this chapter, I will discuss the findings of this study in relation to the relevant literature and make recommendations related to the initial aims of the study. Next, I will describe the limitations of this study and outline the implications for future studies and research in this area. Finally, I reflect on the study and its outcomes.

5.2 SUMMARY

Chapter One presented the motivation for undertaking this study as well as an overview of the proposed study. My involvement in the project on the quality of life of learners with disability, initiated in 2001 by the Department of Educational Psychology at Stellenbosch University (SU), awakened my interest in the subject. I noted the focus and efforts of many parties on supporting the child with a disability. The parents, and at times their child with a disability, attended these project meetings and thus their voices were heard. However, there was little mention of the siblings and *their* difficulties, successes and experiences. This motivated me to explore the experiences of these siblings and make their voices heard in these families.

Chapter Two looked at available literature. Areas of interest to me for purposes of the study were predominantly related to: phenomenology, the perspectives and social effects of disability, experiences of siblings, the support offered to families and siblings specifically, family experiences and coping experiences of siblings and families. I located only a small number of studies on the experiences of siblings 'in their own words'; most research tended to be quantitative in its method.

The methodological approach of the study, research design and techniques used in data collection and analysis were discussed in Chapter Three. An interpretive approach was adopted since the aim of the study was to gain insight into the

experiences, as described in the participants words, in detail and depth (Smith & Eatough, 2006:327). Mertens (1998:8) notes that the main characteristic of this approach is that the participant's reality is socially constructed and so multiple realities exist. Phenomenological theory supports the interpretive paradigm as it focuses on reality as expressed by the participant.

The implementation of the study was discussed in Chapter Four. This chapter described the actual execution of the study which was set out in Chapter Three. Participant details were documented, as was a data trail of activities and their timing. The data collection was documented and the results of interviews were transcribed and presented. Finally, the results were analysed and interpreted.

This final chapter discusses the findings and limitations of this study. It looks at implications and recommendations for future studies.

5.3   DISCUSSION OF FINDINGS

When analysing data according to the interpretive approach, themes are discussed with relation to available current literature (Willig, 2001:60). A discussion of the findings from the data analysis follows.

Russel et al. (2003:36) spoke of unusual opportunities and unusual concerns and needs, recognising that "siblings of children with disabilities experience both good and bad feelings", these could either provide growth opportunities or could create difficulties and stressors for a sibling. Similarly, two main categories of experience were found in this study, namely experiences of difficulty and anxiety, and constructive experiences and positive feelings. These experiences are discussed below.

5.3.1   Experiences of difficulty and anxiety

Feelings of discontent and stress in this study included the experiences of frustration, irritation, annoyance at stubbornness and anger. At times these experiences may be internalised by participants. All of the participants in this study reported either the experience of annoyance at stubbornness or of irritation. Findings by Hollidge (2001:20) and Ligthart (2002:71) both reported the siblings' experiences of anger. Meyer and Vadasy (1996:8) noted the experience of anger at a sibling's actions. While Russell et al. (2003:37) and Strohm (2001:49) did not report the

experience of anger; they did note a sibling's feeling of resentment due to unequal treatment and additional time spent with a child with a disability. Ross and Cuskelly (2006:83) noted high levels of aggressive sibling interaction. Anger, on behalf of the sibling without a disability, was reported as the most frequent response to aggressive interaction (Ross & Cuskelly; 2006:83). This corroborates findings of irritation and frustration felt by participants in the present study.

The feeling of embarrassment appeared to be a universal experience in this study, but to differing degrees. It is commonly mentioned in the literature. Strohm (2001:49) and Stalker and Connors (2004:226) reported participants' feelings of embarrassment about a sibling's appearance or behaviour. Similarly, Meyer and Vadasy (1996:20) reported the experience of embarrassment in front of friends or in public. Burke (2004:84) found that experiences of embarrassment were linked to the awareness of attention being drawn to him or herself through the behaviours of the siblings with a disability. These experiences corresponded with the present study and the participants' accounts of embarrassment in certain social situations and when the sibling performed certain behaviours in public.

This study identified conflict feelings as a main cluster. This field encompasses feelings that are experienced and commonly internalised due to their confusion or the perception of them as being unacceptable feelings. Hollidge (2001:22) mentioned guilt as the overriding feeling experienced by 'well siblings'. He noted the worry about a sibling and the accompanying guilt, as well as survivor guilt that is experienced by the 'well sibling'. Half the participants in this study reported specific accounts of feeling ashamed and guilty about their negative feelings. Participant's accounts of 'feeling bad' may refer to survivor guilt and being the sibling who can do things his brother can't do. On a similar note, Pit-ten Cate and Loots (2000:400) reported the 'well' siblings' feelings of guilt at their own health. Hollidge (2001:23) inferred that well siblings tended to internalise their difficulties and not share them with others. Internalisation of feelings in this study may be seen in sibling's resignation toward their sibling's disability. While experiencing distress they feel helpless to address this. One participant compared her siblings disability to "a wart, ... it grows on you". Avoidance, while only briefly mentioned in the selected literature, could be closely linked to passive acceptance, but in this study it reflects an element

of denial. Burke (2001:79) classifies denial as a defence mechanism to avoid facing reality. One participant acknowledged his embarrassment, only to deny shortly thereafter that he experienced any embarrassment about his sibling. Hollidge (2001:22) found that siblings "felt it necessary to reduce 'unacceptable' feelings of jealousy, anger and competition, [which] can result in experience of shame." Strohm (2001:49) noted that a sibling's shame about their negative feelings could result in low self-esteem.

The experiences of distress and fear were categorised as anguish in this study. Hollidge (2001:20) noted distress and sorrow regarding a sibling's illness. The present study reported accounts about "feeling bad" (P3, line 104) about a brother or sister and fearing for their safety. Concern for perceived difficulties reflected the distress and worries that one participant experienced; "it's horrible to see how … what she's going though" (P2, line 55).

Uncertainty about how to explain to others about a sibling's disability was reported by a participant, and this appeared to increase anxiety when confronted with questions and attention from other people. Opperman and Alant (2003:442) help relate this experience of uncertainty about being able to cope. They stated that developing coping processes can be assisted by ensuring siblings are provided sufficient information about the facts and consequences of their sibling's disability.

Participants noted feelings of sacrifice related to various routines and practices. The time that had to be made to be involved in sibling's activities was reported, and lack of reciprocity was evident. Adapting and being available to a sibling's needs was frequently described. All participants noted protecting and care giving, or looking after a sibling to some degree. This finding was strongly supported in the literature. Strohm (2001:49) noted the increased responsibilities and care-giving demands made on siblings. Similarly Hannah and Midlarsky (2005) reported increased levels of 'helping behaviours' in areas of emotional, and protective or 'guardian' type, care. Concern about a sibling taking on care-giving responsibilities is a contentious issue (Burke, 2004:68). Dyson, Edgar, and Crnic (as cited by in Caro & Derevensky, 1997) state that "when a parent asks a child to provide child care for a sibling", an imbalance in roles may occur and siblings may take on roles of submission and authority. Parentification can occur when a child assumes parental roles. Byng-Hall

(2002:376) noted adverse developmental affects on children who maintain prolonged roles of caring and take on responsibility for emotional wellbeing of family members. This study did not look into the depth and duration of care giving and its effects on participants, but it warrants mention as a possible topic of future study.

Findings of differential treatment were verified in selected literature. When comparing families from different contexts, McHale and Pawletko (1992:74) stated that the differential treatment of siblings was greater in families of a child with a disability. Experience of differential treatment was evident in three main areas, namely in the area of punishment which was seen as lacking when a brother or sister with a disability did not pull their weight. Secondly, the allocation of tasks was unevenly distributed since a sibling with a disability often did not do tasks or chores and was let off lightly. Lastly in expectations of performance, participants spoke of the expectation of doing better in schoolwork and the pressure that they felt was on them to perform in the sports domain. Meyer (1993:3) noted pressure to achieve in the areas of sport and academics. One participant felt in a certain situation that "a lot" was at times expected of him, and to another participant the experience of necessity to play a large amount of sport seemed unfair as well as tiring. Similarly Strohm (2001:49) reported that siblings perceived additional academic and sport-related demands to achieve, "in order to make up for the limitations of the other child".

Plans for, and implications in the future for a sibling with a disability did not emerge as a major experience of concern for participants in this study. While the older participants' siblings' had considered possible future plans: "so I have wondered about what will happen and who will support her if something should happen to my parents and stuff … 'cos they've paid for her stay there." (P2, line 266); they appeared secure in the thought that they would provide some form of support for their sibling should anything happen to parents: "she's self sufficient. But obviously we will support her when my parents stop working, and that's, um … pretty obvious" (P2, line 246); "because we live on a farm I think he will always um be able, always some sort of home on our farm" (P4, line 268). Smith, Greenberg and Seltzer (2007:36) found that "siblings are prepared to play a significant role in assisting their brother or sister … and to maintain family bonds through visits and holiday celebrations."

5.3.2 Constructive experiences and positive feelings

Half the participants spoke of the feeling of being cared for by their sibling with a disability and were moved by the expression of their sibling's love and affection for them. Similar reports were evident in the literature. Wilson (2004:90), for instance, reminisces about her sister who "never hesitates to console me with words of encouragement … or a well timed hug" see introductory section of Chapter One).

Two participants mentioned their brother's or sister's ability and self-sufficiency or independence. One participant mentioned her sister's ability to live apart from the family and carry out a type of job in that environment, thus implying some degree of self sufficiency. The other participant spoke at length about his feelings of admiration at his brothers handling of a certain situation. His account was heartfelt and indicated pride and respect for his brother. As noted by Meyer and Vadasy (1996:21), siblings may feel proud at their brother or sister's accomplishments.

Stalker and Connors (2004:228) found that most siblings saw their brother's or sister's as "unique individuals and, in that sense, like everyone else". This feeling of acceptance was noted in the present study since no participant reported wanting to change their sibling with a disability. It appeared that participants had formed an attachment to, and reported liking and being used to their sibling "as they are". Correspondingly, as reported by Stalker and Connors (2004:228), participants did not see disability as something to be corrected, taken away or regulated.

A common experience, particularly among the older participants, was the experience of personal growth. A mature outlook, awareness and open mindedness were reported by the older participants and increased opportunities and independence were reported by three of the four participants. The literature presents a similar picture: maturity, responsibility, altruism and tolerance are qualities noted by Lobato (Cited in Pit-ten Cate & Loots, 2000:400); Dodd (2004:42) highlights parents' recognition of the importance of their child's increased independence; and Meyer and Vadasy (1996:25) observe that these siblings often develop an understanding of the needs of others and an awareness of when others experience difficulties. They describe this sibling's enhanced maturity in ways such as patience, wisdom and strength that other children may not have attained.

Experience of close, trusting friendships was collectively reported by all participants. This may in part justify the absence of any mention, by participants, of feelings of loneliness and isolation, which were reported by Opperman and Alant (2003:450) as a prevalent experience.

Another experience or concern mentioned in the literature that did not emerge in the present study was that of identification (Meyer, 1993:3; Strohm, 2001:49). Identification results in an individual worrying about also having aspects of a disability, or developing the impairment or disability their sibling experiences. No participant in this study mentioned fears that they may have, or develop, Down syndrome or related impairments.

An interesting point to note in the present study was that all participants were the younger siblings in the family. While this was incidental in this study, it is worth noting that Burke (2004:29) found that younger siblings experienced predominantly positive experiences. This seems to be confirmed by McHale and Gamble (1987:135) whose study inferred that being an older sister of a child with a disability was strongly related to the likelihood of experiencing adjustment problems. Lastly, a central feature observed within these families was that of the communicative openness about and acceptance of the disability by family members.

The effects of this family communication and openness can bear reference to the social constructivist point of view. The daily interactional learning and exposure these siblings receive in their family environment may have predisposed these participants to an openness, acceptance and sincerity regarding their siblings' disability that may enhance their resilience. Similarly, familial and societal attitudes toward disability may have influenced these siblings' experiences. The phenomenological paradigm aims to access the individuals' reality as they have experienced it. Therefore this study encouraged participants to describe and express their feelings, freely, and without judgement, and talk about their lived experiences. Participants were at no point led in the interview. Furthermore their anonymity was assured. Thus it can be assumed that their accounts and experiences are their reality and expressed as such in words and language that were comfortable to them. However, as with any study there were limitations.

5.4   LIMITATIONS

Since this study was conducted in a real world situation, there are natural complications and obstacles that may impose or imply limitations on the study. Particular limitations are discussed below.

- Concerns regarding sample or participant selection are called selection bias (Bless & Higson-Smith, 1995:81). This questions the equivalence of groups. In this qualitative case study the participants were not randomly selected, but selected according to the presence of certain specific criteria. This means that many other personal and contextual variables may have been overlooked. Hollidge (2001:23) notes this as a limitation in his study: "randomizing the sample would have been useful to make it more generalisable. Unfortunately, a large enough sample to create randomisation was not available. The lack of a control group prevented comparisons of our findings with children who did not live with chronically ill siblings."

- Related to sampling or participant selection, the issue of representation of the population is relevant. In the case study approach, however, Flick (1998:72) illustrates a case as representative in the respect that it represents itself, a specific context, and represents a "developed subjectivity".

- The small sample size of a study may limit its generalisability. However, Bless and Higson-Smith (1995:96) defend this as being "less accurate but more convenient".

- The role of language, as noted by Willig (2001:63), is a limitation in interpretive phenomenological analysis. Since phenomenology aims to understand the individual's actual experience, language is relied on as the tool with which to express this. The participant's language use and ability to represent experience in words can greatly affect their portrayal of their experience. It was noted that the younger participants in this study had a narrower emotional vocabulary and often used the same words and sentiments when answering a variety of questions. It appeared at times they were at a loss for words as they would hesitate or pause and repeat what they had previously said. As stated by Danaher and Briod (2005:218) when children, or other people, cannot find the

words to express themselves, the researcher or listener may have difficulty in accessing their experience: "The researcher must wait for language".

- Bless and Higson-Smith (1995:81) note that the 'reactive effects' of being in a study must also be considered. Knowing he or she is part of a study can affect the child's response styles and behaviour when being asked certain questions.

- Participant commitment proved a limitation in this study. Tredoux (1999:326) discussed participant dropout as a realistic threat to validity. This is a limitation that can result in incomplete data. Certain participants frequently cancelled or forgot appointments. The completion of the anamnesis proved difficult to ensure and had to be re-sent, and participants contacted frequently to request if the anamnesis was complete and could be collected. The anamneses of one participant were never completed. Fortunately in this study I had other information I could use such as the literature review and my observations.

- The credibility of findings can be extended through obtaining supplementary collateral information regarding the participant from relevant individuals in the participants' life, such as the class educator. As Mertens (1998) postulates, utilising several methodological techniques and different kinds of data can give a fuller, richer idea of reality. In addition, providing more pictorial information could enhance the aspect of validity in this study through richer, improved triangulation.

Above limitations may be seen as weaknesses in this study. Thus, as in any study, measures were taken to increase validity and reliability, as discussed in Chapter Three.

5.5   IMPLICATIONS AND RECOMMENDATIONS

It appears that in the Western Cape there are currently no sibling-focussed support services besides private care which proves expensive. Studies (Dodd, 2004; Strohm, 2001; Pitman & Matthey, 2004) have demonstrated the effectiveness of these sibling support workshops and thus a primary recommendation for future study relates to the provision of support programmes. Recommendations for future studies may initially aim to raise awareness of the needs of siblings and subsequently determine the extent of this need for support groups or workshops, who will commit to using

these services, in what areas these projects should be based, and how they should be structured. There is clearly vast scope for further research into the support needs of these siblings of a child with a disability in the Western Cape.

Another direction of study may find it useful to explore how parents' coping responses and reactions to disability in the family affect other children's experiences of and coping responses when dealing with the child with a disability. An understanding of how a parent can support or undermine their children's adjustment and coping is important in deciding on how best to support for the sibling without a disability as well as for the family. One suggested framework in the quest for a way forward is discussed briefly below.

5.5.1 The way forward

This chapter would be incomplete without reference to a way forward that could facilitate the development of support programmes. Although this is only one framework or a set of guidelines, it may be useful in enabling us to foster resilience in any child, and help build and develop characteristics and skills for life. Studies have shown the associations between the mentioned assets and favourable youth outcomes. They have also shown connections between assets at one stage and favourable outcomes years later (Sesma, Mannes & Scales, 2006:283).

The Developmental Asset Framework proposed by Sesma et al. (2006:283-284) looks at two main qualifications of assets that assist in beneficial development of the individual. It looks at internal and external assets. Within these two main asset groups, there are four sub-categories, each in turn populated by definitions of these assets (See Appendix 10). This model assumes that the more positive the experiences the individual possesses are, the more likely they are to succeed developmentally (Sesma et al., 2006:285). The use of this model in conjunction with the understanding of needs and issues that a sibling may experience can provide a basis from which to offer support. This model can be useful in developing competencies, and can be used in support and development programmes for any child, at risk or not.

5.6   CONCLUSION AND REFLECTION

Chapter Five concluded this thesis by discussing findings from Chapter Four and relating them to literature as discussed in Chapter Two. The limitations encountered during this study were explained and implications for further study were discussed.

My personal experience during this study is important. While finding this study challenging at times, I frequently found myself reflecting upon my own personal experiences. I became aware of my preconceptions of sibling relationships in relation to my own experiences. Although my brother did not have a disability, I have come to realise the profound effect that each sibling has on the other, and consequently on the family unit. Throughout the study, I had to remain conscious of as many of my assumptions and beliefs as possible, and be aware that these could affect my interpretation of certain data.

In closing, I found these siblings made me aware of a sense of acceptance and also appreciation for all they have. This study was personally rewarding for me in many ways, through the challenges it provided and more so through the remarkable families and individuals I was privileged to meet.

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ADDENDUM 1

PERMISSION FOR USE OF SIBLING QUESTIONNAIRE

PERMISSION FOR USE OF
THE SIBLING QUESTIONNAIRE

From: P.C.Burke@XXXXX.uk [mailto:XXX@XXX.XX.uk]
Sent: Wed 2007/01/24 12:33
To: Sarah <XXX@XXX.ac.za>
Subject: Re: Children's experiences when a sibling has Down syndrome

Hello Sarah
the questionnaire used is at the back of the book. The pilot study was more or
less the same questionnaire. It could be used by you if you cite it as such,
and has I believe been used by others. Perhaps as an educational psychology
intern you may need to use various interval scales to measure attributes
related to sibling experiences and there are many such scales although I have
not use such for many years. You could certainly build on my questionnaire as
you need for your thesis.

Good luck

Kind regards

Peter

Quoting "Robinson, Sarah <xxx@sun.ac.za>":

> Dear Mr Burke,
> I am an Educational Psychology Intern in South Africa and am currently writing
> my thesis on the above topic.
> I have found your book the most useful work available to me thus far.
> (Brothers and Sisters of Disabled Children, Jessica Kingsley Publishers,
> London).
> I am in the early stage of my research and I was wondering if it is possible
> to obtain a copy of the questions you used in your pilot study when
> interviewing children about their experiences when their sibling has a
> disability?
> Is this questionnaire available for use in other studies?
>
> Thank you for your help. I look forward to hearing from you.
>
> Regards
> Sarah Jervis
>

****
To view the terms under which this email is distributed, please go to http://www.disclaimer.html

ADDENDUM 2

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR USE BY PARENTS/LEGAL GUARDIANS

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR USE BY PARENTS/LEGAL GUARDIANS

TITLE OF RESEARCH PROJECT: Exploring the experiences of the sibling of a child with a disability.

*PRINCIPAL INVESTIGATOR: **S. Jervis***

CONTACT NUMBER: 021 555 5555/ 083 555 5555

Your child *(or ward, if applicable)* is being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how your child could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you or your child negatively in any way whatsoever. You are also free to withdraw him/her from the study at any point, even if you do initially agree to let him/her take part.

What is this research study all about?

This study aims to looks at the experiences of a sibling when a child in the family has a disability. The study falls within a larger study looking at the quality of life of learners with Down Syndrome. This project was initiated in the year 2001 as a partnership between Down Syndrome South Africa (a non-governmental organisation) and the Department of Educational Psychology at Stellenbosch University (SU).

The area of disability and inclusion is a greatly researched and publicised domain. In the family situation, when a child has a disability, in this study Down syndrome, much time, energy and resources are being focussed on the child with a disability. Gorelick (1996) mentions the child who may at times become "virtually invisible" amongst the vast scope of research, literature, support and information provided for their sibling with a disability. (Gorelick, 1996, p3).

By gaining a more adequate understanding of the siblings experiences, we can gain insight and rich information to assist in development of support programs that will benefit the sibling, and in turn the family.

The research takes a qualitative stance, which looks at the meanings, understandings and personal accounts of experience. The individuals own words are of importance. These words and experiences are obtained through an interview with the participant.

Why has your child been invited to participate?

The project is focussed on the effects of intellectual disability. Thus siblings of a child, who has been identified with a disability, were purposefully selected for the study. Participants are requested to volunteer. The parents of minor children will sign consent.

What will your responsibilities be?

Requirements are mainly those of availability. An initial meeting, if possible, with the family to introduce the study and answer any questions any family member may have. A parent will be required to complete anamnesis forms detailing personal information regarding the child. The sibling/ participant must be available and willing to take part in a single interview. (At family's convenience)

Will your child benefit from taking part in this research?

While there may be no personal benefits for the sibling from this single interview, it is hoped that information gained from this research will provide insight into concerns and needs of siblings when a brother or sister has a disability, and consequently aid in developing programs for support of siblings.

Risks that may arise are primarily emotional in nature, as talking about personal experiences, feelings and issues related to disability within the family may give rise to a range of feelings during and after the interview.

If you do not agree to allow your child to take part, what alternatives does your child have?

This is a single interview and, while endeavouring to contain and protect the child during the interview process, it does not qualify in any way as treatment or therapy.

Will you or your child be paid to take part in this study and are there any costs involved?

You or your child will not be paid to take part in the study, but there will be no costs involved for you if your child does take part.

Is there any thing else that you should know or do?

You can contact the researcher, Sarah Jervis, at any point to request additional information or discuss any concerns you may have. (021-555-5555)

You will receive a copy of this information and consent form for your own records.

Assent of minor

*I (***Name of Child/Minor***)…………………………………………. have been invited to take part in the above research project.*

- The researcher and my parents have explained the details of the study to me and I understand what they have said to me.

- They have also explained that this study will involve.

- I also know that I am free to withdraw from the study at any time if I am unhappy.

- By writing my name below, I voluntary agree to take part in this research project. I confirm that I have not been forced either by my parents or doctor to take part.

....
Name of child   *Independent witness*
(To be written by the child if possible)

Declaration by parent/legal guardian

By signing below, I (name of parent/legal guardian) …………………………………..……. agree to allow my

child (name of child). ………………………………… who is ………. years old, to take part in a research study

entitled 'Exploring the experiences of the sibling of a child with a disability'.

I declare that:

- I have read or had read to me this information and consent form and that it is written in a language with which I am fluent and comfortable.

- If my child is older then 7 years, he/she must agree to take part in the study and his/her ASSENT must be recorded on this form.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to let my child take part.
- I may choose to withdraw my child from the study at any time and my child will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished if the researcher feels it is in my child's best interests.

Signed at (*place*) ....….......………….. on (*date*) …………...……….. 2007.

....
Signature of parent/legal guardian

....
Signature of witness

Declaration by investigator

I *(name)* ………………………………………..……… declare that:

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understand all aspects of the research, as discussed above
- I did/did not use an interpreter (i*f an interpreter is used, then the interpreter must sign the additional declaration).*

Signed at (*place*) ....….......………….. on (*date*) ………….....……….. 2007.

....
Signature of investigator

....
Signature of witness

ADDENDUM 3

INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

Questionnaire for siblings (Burke, 2004)

Questionnaire amended. Added questions are in *italics*.

Sibling relationship:

Today I'd like to talk about you and your brothers/ sisters, how many do you have?

How do you get along with each other?

Can you tell me some more about … (sibling with disability)?

Who told you what is wrong with ….?

How does having a sister/ brother with Down/ Noonan syndrome make you feel?

1. What is the best part about having a sibling with a disability?

2. What is the worst part about having a sibling with a disability?

3. Do parents expect too much?

4. What do they expect?

5. Give examples of caring, playing, being involved with your brother or sister.

What changes do you have to make to your life because of x?

How do you feel about that?

6. Have you ever been embarrassed by your brother or sister? Give examples.

Are there things that you can't do (or are difficult to do) because of …?

Can you describe some examples?

What do you think will happen to him/ her in the future?

School relationships:

When your friends or strangers ask you about …, what do you tell them?

How do you think they feel about …?

7. Have these been difficult as a result of having a disabled sibling? Give examples.

8. Have you ever felt it difficult to bring friends home? Give examples of the difficulties.

9. Do you feel you are any different from other young people because of your experience? Give examples.

10. Any other issues?

Magic wand question: what would you most like to change to improve your life if you had a magic wand (anything at all)?

ADDENDUM 4

QUESTIONNAIRE 1

UNIT FOR EDUCATIONAL PSYCHOLOGY

UNIVERSITY OF STELLENBOSCH

QUESTIONNAIRE 1

(Please indicate with ✶ where applicable)

CHILD

SURNAME		DATE OF BIRTH	/ /
CHRISTIAN NAME(S)		FIRST NAME	

HOME LANGUAGE

Afr	Eng	Xhosa
Other		

AGE

yrs	months

HAVE YOU PREVIOUSLY SOUGHT ADVICE ABOUT THIS MENTIONED CHILD?

Yes	No

IF "YES"

PLACE/PERSON	DATE

PARENT(S)/GUARDIAN

	DETAILS OF FATHER	DETAILS OF MOTHER
OCCUPATION		
OCCUPATION BEFORE MARRIAGE		
WORKING HOURS		
QUALIFICATIONS		
AGE IN YEARS		

HOME LANGUAGE

Afr	Eng	Xhosa	Other:		Afr	Eng	Xhosa	Other:

MARITAL STATE

Married	Never married	Widower	Widow	Divorced	In process of divorcing	Estranged	Living together

HOME ADDRESS	POSTAL ADDRESS

ADDENDUM 5

QUESTIONNAIRE 2

UNIT FOR EDUCATIONAL PSYCHOLOGY

UNIVERSITY OF STELLENBOSCH

QUESTIONNAIRE 2	NAME:	

Indicate with ✓

NURSERY SCHOOL

1. If this child attends/has attended nursery school:

SCHOOL	
PERIOD	
SCHOOL PRINCIPAL	
TEACHER	

2. Did the teacher identify any problems? | YES | NO |

   If YES, describe briefly:

   _____

   _____

3. Do you judge that your child is / was ready for school? | YE S | NO | UNSU RE |

DEVELOPMENTAL DETAILS

A. Physical

1.   Pregnancy

1.1   Was it a | normal | unknown | problematic | **pregnancy?**

   If problematic, describe briefly: _____

   _____

1.2   Was infertility a factor in this pregnancy? | YES | NO |

1.3   Was this pregnancy planned? | YES | NO |

1.4   Duration of the pregnancy? | normal | premature (36 weeks or less) | postmature (more than 41 weeks) |

   If premature, how many weeks? | |

1.5   Age of mother at the birth: | |

2. __Birth__

2.1 Was the **birth** | normal | problematic (e.g. forceps or suction delivery); umbilical cord around neck |

| Caesarean section | induction | unknown | ?

If problematic, describe: _____

_____

If Caesarean section, why?_____

_____

If induction, why? _____

_____

2.2 Duration of normal birth: | normal | long: _____ hrs | short: _____ hrs |

2.3 Appearance of baby after birth: | blue | pink | yellow | marks on head | other: |

2.4 Was oxygen administered after birth? | **YES** | **NO** |

If YES, why? _____

2.5 Was the baby placed in an incubator? | **YES** | **NO** |

If YES, why? _____

For how long? _____

2.6 Birth weight: | normal (2,7 – 4 kg) | lighter: _____ kg | heavier: _____ kg |

2.7 Apgar score: | |

3. __Feeding__

3.1 Type of feeding after birth: | breast up to _____ months | bottle up to _____ months |

3.2 Any feeding problems during infancy? (e.g. colic, sucking reflex) | **YES** | **NO** |

If YES, describe: _____

_____

3.3 Any feeding problems as toddler or at present? | **YES** | **NO** |

If YES, describe: _____

_____

4. Motor development

4.1   Sit   : | normal stage (6 – 8 months) | sooner | later |

4.2   Crawl : | normal stage (8 – 10 months) | sooner | later |

4.3   Stand : | normal stage (9 – 11 months) | sooner | later |

4.4   Walk   : | normal stage (12 – 14 months) | sooner | later |

4.5   Control over big movements, e.g. running: | clumsy | average | quick |

4.6   Control over small movements, e.g. threading beads: | clumsy | average | good |

4.7   Toilet training: During the day: | under 2 yrs | 2 – 3 years | after 3 years |

During the night: | under 2 yrs | 2 – 3 years | after 3 years |

5. General health

5.1   Has your child had all the prescribed immunisations? | *YES* | NO |

5.2   Specify all **illnesses,** the **ages** at which your child had them, whether accompanied by high **temperature** and whether your child was **hospitalised** for the specific illness:

_____

_____

5.3   Specify all **injuries** and **operations** and **age** at particular time:

_____

_____

5.4   Is this child physically handicapped? | **YES** | *NO* |

If YES, describe: _____

_____

5.5   Has this child had | convulsions | loss of contact (black outs) | ? | **YES** | **NO** |

If YES, describe (indicate age at time): _____

_____

5.6   Does this child have any allergies? | **YES** | **NO** |

If YES, specify: _____

_____

5.7 In your opinion, is your child's general health | good | average | weak | ?

5.8 Does your child take any medication AT PRESENT? | **YES** | **NO** |

If yes, please provide the information below

Name of medication	Dose	Period used	Reason for prescription

Has your child taken his/her medication before coming to the Unit today? | YES | NO |

5.9 Does any other member of your family suffer from a serious or chronic illness? | **YES** | **NO** |

If yes, please specify

Which family member?	Kind of illness	Length of time

5.10 Please indicate if any member of your family suffers from psychiatric problems (e.g. depression, eating disorder, etc). | **YES** | **NO** |

If yes, please specify

Which family member?	Kind of illness	Length of time

6. Sensory Development

6.1 Vision: | good | problematic | do not know |

6.2 Hearing: | good | problematic | do not know |

B. *Language and Speech*

1. Words: | normal stage (10 – 14 months) | sooner | later |

2. Interest in stories: | great | average | not at all |

3. Ability to repeat a story: | good | average | poor |

4. Problems with word building? | **YES** | **NO** |

5. In your opinion, is this child's language development | good | average | poor | ?

6. Any speech problems? | **YES** | **NO** |

If YES, specify and indicate whether your child was examined in this connection:

_____

_____

QUESTIONNAIRE COMPLETED BY:

| FATHER / MOTHER / OTHER: | DATE:_____/_____/_____ |

ADDENDUM 6

QUESTIONNAIRE 3

UNIT FOR EDUCATIONAL PSYCHOLOGY

UNIVERSITY OF STELLENBOSCH

QUESTIONNAIRE 3	NAME:

Indicate with ✓

A.   EMOTIONAL

1.   Does/Did your child suffer from enuresis (bedwetting)?   **YES** | **NO**   When? _____

If YES, has your child been examined by a doctor?   **YES** | **NO**

Finding: _____

2.   Does/Did your child suffer from encopresis (fouling)?   **YES** | **NO**   When? _____

If YES, has your child been examined by a doctor?   **YES** | **NO**

Finding: _____

3.   Please indicate with regard to your child (underline where applicable):

sleeplessness / somnambulism (sleep walking) / nightmares / talking in sleep / restless

sleeping / easily frightened / nailbiting / tantrums / fear of darkness / tics / exceptional

need for pampering / considerable self-confidence / average self-confidence / little self-

confidence / independent / reasonably independent / very dependent on parents /

fluctuating emotions / thumbsucking / tense / cries easily / cries often / any phobia:

_____

B.   SOCIAL

1.   How does your child get on with friends?   well | moderately | poor

2.   Does your child prefer to play   alone | with friends   ?

3.   Child's play: imaginative | average | needs guidance

C.   PERSONALITY

1. **Is your child:** moody / rebellious / shy / independent / solitary / inclined to jealousy /

careless / obedient / easy to manage / attention seeking / exceptionally tidy / untidy / a

day-dreamer / selfish / domineering / active / quiet / enthusiastic / easily distracted /

attentive / appreciative of aesthetics / loving / a leader / cheerful / humorous / responsible

/ spontaneous / self-controlled / sympathetic / helpful / dishonest / honest.

2. Any other outstanding personality traits: _____

_____

D. DISCIPLINE

1. How does your child accept discipline at home? | well | badly | badly at times |

   If badly, describe: _____

   _____

2. How does your child accept discipline from others? | well | badly | badly at times |

3. Whose authority does the child accept most readily? | father | mother | both | others |

   _____

4. Which form of punishment is most effective with your child?

   | Talking | loss of privileges | corporal punishment | other: |

5. Do you feel you can discipline this child and your other children effectively? | YES | NO |

E. ADDITIONAL FAMILY BACKGROUND

1. How does your child get on with other members of the family? | well | badly | well with some |

2. Does your child have a special bond with a particular family member? | YES | NO |

   If YES, with whom? _____

3. Is your child hostile towards family members? | YES | NO |

   If YES, to whom?

   _____

4. Do you experience similar problems with your other children? | YES | NO |

   If YES, with whom and describe: _____

   _____

5. Are your child's grandparents still alive? | YES | NO |

5.1 If YES, do they have a strong influence on his/her upbringing? | YES | NO |

   If YES, describe: _____

   _____

_____

6. Was the father/mother at any stage separated from the child for an extended period of time?

| YES | NO |

If YES, state who, the child's age at that time, what the circumstances were and how the child

reacted: _____

_____

7. If applicable, how did your child react to the arrival of a new baby?
_____
_____

8. Do you read on child development and education? | often | sometimes | never |

9. How does your child spend his/her leisure time? _____
_____

10. Do you participate as a family in some activities?

| YES | NO |

If YES, describe and how often: _____
_____

11. Does this child/your other children talk freely with the mother/father about their

problems?

| YES | NO |

12. If the mother has worked/has been working since the birth of the children:

Period(s): _____

Half/Full day: _____

F. INTELLECTUAL ABILITY

1. How do you rate this child's intellectual ability?

| | very intelligent   average intelligence   below average intelligence |

2. Is your child's concept of number | good | average | poor | ?

3. How do you rate your child's language development (e.g. vocabulary, reasoning,

comprehension)? | good | average | poor |

| | | |

4. How do you rate your child's long term memory?   good   average   poor

5. How do you rate your child's short term memory? | good | average | poor |

QUESTIONNAIRE COMPLETED BY:

| FATHER / MOTHER / OTHER: | DATE:_____/_____/_____ |

ADDENDUM 7

QUESTIONNAIRE 4

UNIT FOR EDUCATIONAL PSYCHOLOGY

UNIVERSITY OF STELLENBOSCH

QUESTIONNAIRE 4	NAME:

Indicate with ✓

SCHOLASTIC BACKGROUND

1.   Present school: _____   Grade: _____

Medium of instruction: Afr / Eng / Xhosa / Other:

2.   Which schools has your child attended? State dates of admission and departure:

School	Date of admission	Date of departure

3.   Was/is he/she a boarder?   **YES / NO**   If YES, which phase?   primary school / high school / both

4.   How did your child adjust to these conditions?   well / reasonably / badly

5.   How did your child adjust when he/she went to school for the first time?   well / reasonably / badly

6.   Has your child at any stage refused to go to school?   **YES / NO**

      If YES, when and why: _____

7.   What is your child's attitude to school?   good / reasonable / poor

8.   What is your child's attitude towards the teacher(s)?   good / reasonable / poor

9.   Has your child ever changed his/her attitude to the school/a teacher for some reason?   **YES / NO**

      If YES: positive or negative?   In your opinion, why?_____

10. Does your child achieve according to / below / above his/her ability ?

11. How does your child feel about his/her scholastic progress?

satisfied / worried / unconcerned / I do not know

12. Does your child's achievement vary from day to day? often / never / sometimes

13. Has there at any stage been a sudden deterioration in your child's achievement? **YES / NO**

If YES, what in your opinion could the reason be?

_____

_____

14. Has your child ever failed? **YES / NO**

If YES, which grade and in your opinion, why?

_____

15. Does your child have problems with any specific subject(s)? **YES / NO**

If yes, which subjects(s)?_____

16. **Homework**

16.1 Do you judge your child's homework to be too much / too little / enough ?

16.2 Does your child do his/her homework alone / under supervision of the parent(s) / alone, but parent(s) assist when necessary?

16.3 Do you check his/her homework after it has been done? always / sometimes / never

16.4 Does it happen that your child knows his/her work at home, but not at school?

always / sometimes / never

16.5 How long does it normally take your child to finish his/her daily homework? _____ hour(s)

16.6 Has your child ever cried about homework? **YES / NO**

If YES, what in your opinion could the reason be:

_____

16.7 Does your child have a suitable place where he/she can do his/her homework? **YES / NO**

16.8 Does your child have a fixed routine in the afternoon/evening which includes the doing of homework?

YES / NO

16.9   What time does your child go to bed during the week?_____

16.10   How much TV does your child watch per day during the week? | 1 hour / 2-3 hours / more than 3 hours |

16.11   Does your child exercise during the week? | never / irregularly / regularly / heavily |

QUESTIONNAIRE COMPLETED BY:

| FATHER / MOTHER / OTHER: | DATE: _____/_____/_____ |

ADDENDUM 8

DATA TRAIL

DATA TRAIL

Date	Client/ Family & contact person	Contact type & duration	Details	My Reflections
26 Feb	Family 3: mother	Telephonic discussion: 5 minutes	Planning of times for initial family meeting and child interview	Willing and prepared to be part of study
Feb	Family 1: mother	Telephonic discussion: 15 minutes	Planning of times for initial meeting and child interview	Open and prepared to share information about experiences and prepared to be part of study
6 March	Family 3: mother	SMS received to cancel interview on 8 March	Cancelled due to recent family plans. Meeting moved to after school holiday.	Mother appeared to have much to deal with and couldn't commit to certain future date
8 March	Family 1: children and mother	Meeting at family home: 1 hour	Mother and children present	
13 March	Participant1	Interview: 30 minutes	Interview	Willing and available, however distracted by tape recorder and very aware of it.
11 April	Family 3: mother	Telephonic discussion: 5 minutes	Reschedule meeting and interview.	Difficult to commit to date due to children's sport and school schedules
12 April	Family 2: Father	Telephonic message left at parents work. 1minute	Request to contact researcher.	
13 April	Family 2: Mother	Telephone call to mother regarding study. 10minutes	Mother agreed to ask her child if she would be willing to participate. Details regarding study were e-mailed to her.	Mother sounded willing and respectful that her daughter must decide for herself. Thus wouldn't commit on her behalf.
16 April	Family 3: mother	Telephonic discussion: 5 minutes	New meeting and interview time scheduled - Fri 20 April.	
16 April	Family 2: was contacted by mothers assistant	Telephonic 3 minutes	Assistant contacted to arrange interview with participant 2	Participant 2 was willing to be available at short notice for an interview that week.
16 April	Contacted physiotherapist	Telephonic. 5 minutes	Physiotherapist able to provide details of last participant (participant 4)	Aware of client who will be willing to participate.
17 April	Attempt to contact Family 4	Wrong number		Re-contact physiotherapist for correct number

Date	Client/ Family & contact person	Contact type & duration	Details	My Reflections
17 April	Father of participant 2 returned call	Telephonic. 5 minutes	I explained the nature of the study and that mother had responded and Participant 2 had agreed to interview.	Father appeared prepared that his child participate and was accepting that I had arranged an interview with her.
17 April	Contact family 1	Telephonic. 5 minutes	Request whether anamneses is completed, and can be collected by researcher.	Anamneses cannot be found. E-mail another set.
18 April	Family 4	Telephonic contact: 7mimutes	Spoke to mother regarding study.	Interested and willing to tell participant 4 about this and to expect my call. She sent me his cel. number to contact him to arrange meeting.
19 April	Participant 2	Interview 50minutes	Researcher met briefly with mother and answered any questions and requested that anamneses be completed when convenient.	Mother busy and on her way out. Participant 2 arrived and was willing to start once she had something to eat.
20 April	Participant 3	Interview 25 minutes	Arrived at house, mother wasn't present but participant 3 was available for interview.	I explained what I was there for and participant 3 was willing to go ahead with the interview. I waited for a parent to arrive home to meet and discuss additional forms. Stepfather arrived and anamneses were left for completion and collection would be arranged.
20 April	Family 2: researcher called assistant to mother	Telephonic: 2 minutes	Called regarding anamnesis. Agreed to pass on message to mother requesting that I collect anamneses following week.	Anamneses not completed yet. Must confirm before collection on 8 May.
20 April	Family 4			
22 April	Participant 1	Telephone call: 2 minutes	Called regarding anamnesis	Mother said she would send an SMS when anamnesis completed.

Date	Client/ Family & contact person	Contact type & duration	Details	My Reflections
22 April	Family 3	Telephone call: 5 minutes	Called regarding interview and to ensure anamnesis received.	Mother apologised for not being available. She was cooperative and willing to complete anamnesis.
22 April	Participant 4	Called and left message	Called regarding interview and asked to miss call me when I can call him back	Message left explaining study briefly and saying I would call back if/ when I received a missed call from him.
23 April	Participant 4	SMS to call him after 9pm that night		
23 April	Participant 4	Called after 9pm a few times and finally reached him.	Interview arranged for that week after school.	Participant 4 was available to make a time to meet and do the interview. He appeared unhesitant and open to the study.
24 April	Participant 4	Interview - 60 minutes	Meet at school and find a quiet and private place to interview.	Participant 4 was prompt and approachable. He expressed himself well I the interview and had much to say. He appeared open and honest. Anamneses and contract were given to him for mother to complete
3 May	Family 4: mother	Postal: Anamneses competed	Received via post	Very prompt completion and return of the consent forms and anamneses.
4 May	Family 1: mother	Sent sms	Requesting when I could pick up completed anamneses	No reply
8 May	Family 2: mother's assistant	Telephonic message: 1 minutes	I could pickup completed anamneses	Completed anamnesis collected
10 May	Family 1: mother	Telephonic: 2 minutes-left message	Called Requesting when I could pick up completed anamneses	She was not available but sent sms late in evening apologising and saying form would be ready on Sat 12 May for collection.
11 May	Family 1: mother	Replied via sms	Confirmed to pick up anamneses on 12	

Date	Client/ Family & contact person	Contact type & duration	Details	My Reflections
			May	
11 May	Family 3: mother	Telephonic: 5 minutes	Called regarding additional questions about sibling and anamnesis. Anamnesis lost so I would email another copy.	I felt this mother had other things to deal with and having to complete these anamneses was becoming a hassle.
12 May	Family 1:	Collected anamneses		Completed anamnesis collected
15 May	Family 3: mother	Email sent with anamnesis		No response
05 June	Family 3: mother	Called family regarding anamnesis		No answer
14 June	Family 3: mother	Sms sent regarding anamnesis		No response
21 June	Family 3: mother	Another email sent with anamnesis		No response
04 July	Family 3			I made a decision to stop contacting this participant's family, as it was apparent that it was not possible to attain the completed anamneses.

ADDENDUM 9

EXTRACT FROM TRANSCRIPTION

OF INTERVIEW OF PARTICIPANT 4

Extract from transcription 04 of Interview of participant 4
on 24 April 2007

P: Participant 4

I: interviewer

(Brother): brother with Down syndrome

After introducing the study, discussing the consent form, requesting consent and signatures.

I: ok to start with can you tell me about your brothers and sisters?

P: I have two brothers. (Brother) is my older brother and he's got Down Syndrome. He's 20 years old. And I have a, a middle aged brother, which is XXX, and he's 18.

I: how do you all get along with each other?

P: our, … I think we all get along very well. Gen… compared to other families I think we actually do get along very well. Um … I don't know, were not sort of the fighting sort of type, we don't really physically fight. Occasionally when we really annoy each other we…we might get aggressive but we either, I usually argue quite a bit with (brother) I'll, like over the remote control, or over the TV or about something. He can be very stubborn which annoys me, … like cos he can, he doesn't um … he doesn't like, ... I don't think he unders … like some things that I try to tell him he doesn't really understand. So he can be quite stubborn and I can get frustrated about that, ...But I'd say that overall we get along well.

I: I am going to ask you a bit about you and you brother now. Can you tell me more about (brother)?

P: well he's short … Well in features??

I: yes and personality ...

P: well firstly he's short and quite well built, he's quite stocky. He's got freckles and brownish hair. Um … personality, he's, he's very friendly and he, I think a lot of personality, well he like talking about his sport. He is very into his sport and he likes watching a lot of sport on TV, umm … and he tried to act mature a lot, he tries to act mature and he , he um I'd say he's very mature for Down syndrome children. But he's still, I'll find like when he tried to act mature when I say something he sometimes he cant act mature anymore and he will start laughing. So he tries to act very mature and ja, he's very friendly, warm, welcome … and he can sometimes get a bit embarrassed about some things, but he's usually very warm and welcome …

(Smiling about "acting mature")

I: ok, somebody must have told you about Down syndrome. Can you tell me about who did or how did they tell you?

P: um, I don't think, um, I don't think anyone told me that was Down syndrome; I think I sort of grew up with it. I always realised that he was different, I mean, I think, I don't know, probably when I was four years old I started realising that there was something that was different. But I suppose slowly as I grew up I started realising the repercussions of being Down syndrome, ja. And I don't know when my parents started using the phase "Down syndrome" to me, but it must have been when I was about six or seven, that's probably when I, ja …

I: and did you ever have specific questions that you asked them?

P: ja, I did, well I was always interested because you, you often will, … actually this is more um in the last few years, he (brother) always asks about getting mar … he always says he's gonna get married and he's going to have children. So I, and I thought, is it like, I didn't know if he was allowed to have children, if it was legal. But then all my friends told me that all Down syndrome children are infertile.

I: oh really, I didn't know that?

P: well that's, well that's what my mom said … so I am not sure exactly … but um, ja that's probably ... and I've always asked like … how clever he is and like and questions like that when I was much younger. I was always interested to see like … Ja …

I: it must have been intriguing cos you must have 'caught him up' mentally?

P: ja ... um I rem, ja, I actually don't know when that happened, I think, um … there were some areas that I can always remember being cleverer than him at. Um and I think that was speech mainly, and I remember he, he showed like, ... I must have been in grade 1 or 2, and he showed me something like a math sum and I didn't understand it at all, … so I think like after, when I had finished grade one I probably was above him.

I: at that point you started to realise?

P: ja, I was cleverer than him.

I: ok, how do you feel having a brother who has Down syndrome?

P: um. I actually think it is more of an advantage than a disadvantage. Um, I think its also, it just, I can imagine if I hadn't had a brother with Down syndrome, it would be quite scary or nerv ... or I am sure I'd be quite nervous when meeting someone with Down syndrome, first hand. SO I think that's a very u, I'm very lucky in that way. Like his friends, I am not scared of them or I, I don't feel nervous around them, and I can, and I know how to relate with them, and I know what to talk about and how to get on. um so I think that's probably been the biggest advantage. But the disadvantage I found is I, I got very embarrassed sometimes. Like if I went to school and he was there … I, I was I was scared like

people would tease me about him. And I was always scared that that would happen, … and it did once, luckily not at my school but at another school ... and um, ... But some of my school mates luckily stood up for me, cos I didn't, I didn't, I dunno, I just didn't want to … I, I didn't stand up for him cos I don't want to, people to tease me …

<center>(Appeared to be feeling aware of this embarrassment)</center>

I: ja, its a very real thing especially the younger you are and the less you understand, and the more you are affected by what others think …

P: ja.

I: What would you say is the best part about having a sibling with a disability?

P: um … the best part … well … I dunno, um, I think always having a sibling is very nice. He's always, I mean if I think of my older brother, he's always been older than me so he's always been doing.. he's always had work to do or something else to do, and I've always sort of hung around (brother) cos he's, he always like, if he's not watching TV you might be able to play cricket or rugby with him. So he's actually been a proper sibling to me, he's always been there. So, I think that was very nice, and maybe because he had Down syndrome, he was always able to play soccer and rugby with me otherwise he probably would have had to be doing homework. But um I think, I think it was also because he had Down syndrome we had to, his education was quite hard, and so we had to um, it was quite hard to like, we had to move into Cape Town and various reasons.

I: what school is he at?

P: he's in the special needs class in XYXYXY.

I: Right, and what is the worst part about having a sibling with a disability?

P: um, um I think well sometimes they can be um, very stubborn, and that frustrates me. And sometimes they can be irritating, and, um, but I suppose that all siblings are like that, so I don't suppose that its necessarily Down syndrome that makes him like that. Um, but I find I get, I'm probably quite self-conscious, so I can get embarrassed quite easily. And um I have ... he has embarrassed me on a few occasions and I've got quite cross, and I mean I know I shouldn't get cross about those sort of things but … like at school if I was busy playing rugby and if he came onto the rugby field and he like um gave me something and everyone just looks at him, and, I, I sort of feel embarrassed, and now that I look back at it, I shouldn't have feel that embarrassed and that angry sometimes …

I: its sort of like different things embarrassed us as we get older and it was one of those things, …

P: ja, … that's very true, ja ...

I: ok, do your parents expect too much from you?

P: in what way?

I: do they ever expect you to do things that you think other people without a sibling with a disability wouldn't have to do?

P: um ... I think sometimes yes but generally not. Mainly with helping out around the house and things like that. And we have to help our parents, then he often

ADDENDUM 10

DEVELOPMENTAL ASSET FRAMEWORK

DEVELOPMENTAL ASSET FRAMEWORK

(Reference: Sesma, A., Mannes, M. & Scales, P. (2006). Positive adaptation, resilience, and the Developmental Asset Framework in: Goldstein, S & Brooks, R (Eds) Handbook of Resilience in Children. Pp.283-284)

EXTERNAL ASSETS

1. Support-**Family support**-Family life provides high levels of love and support.

-**Positive family communication**-Young person and her or his parent(s) communicate positively, and young person is willing to seek advice and counsel from parent(s).

-**Other adult relationships**-Young person receives support from three or more nonparent adults.

-**Caring neighborhood**-Young person experiences caring neighbors.

-**Caring school climate**-School provides a caring, encouraging environment.

-**Parent involvement in schooling**-Parent(s) are actively involved in helping young person succeed in school.

2. Empowerment-**Community values youth**-Young person perceives that adults in the community value youth.

-**Youth as resources**-Young people are given useful roles in the community.

-**Service to others**-Young person serves in the community one hour or more per week.

-**Safety**-Young person feels safe at home, at school, and in the neighborhood.

3. Boundaries and Expectations-**Family boundaries**-Family has clear rules and consequences, and monitors the young person's whereabouts.

-**School boundaries**-School provides clear rules and consequences.

-**Neighborhood boundaries**-Neighbors take responsibility for monitoring young people's behavior.

-**Adult role models**-Parent(s) and other adults model positive, responsible behavior.

-**Positive peer influence**-Young person's best friends model responsible behavior.

-**High expectations**-Both parent(s) and teachers encourage the young person to do well.

**4. Constructive Use
of Time**-**Creative activities**-Young person spends three or more hours per week in lessons or practice in music, theater, or other arts.

-**Youth programs**-Young person spends three or more hours per week in sports, clubs, or organizations at school and/or in community organizations.

-**Religious community**-Young person spends one hour or more per week in activities in a religious institution.

-**Time at home**-Young person is out with friends "with nothing special to do" two or fewer nights per week.

INTERNAL ASSETS

1. Commitment to Learning-**Achievement motivation**-Young person is motivated to do well in school.

-**School engagement**-Young person is actively engaged in learning.

-**Homework**-Young person reports doing at least one hour of homework every school day.

-**Bonding to school**-Young person cares about her or his school.

-**Reading for pleasure**-Young person reads for pleasure three or more hours per week.

2. Positive Values-**Caring**-Young person places high value on helping other people.

-**Equality and social justice**-Young person places high value on promoting equality and reducing hunger and poverty.

-**Integrity**-Young person acts on convictions and stands up for her or his beliefs.

-**Honesty**-Young person "tells the truth even when it is not easy."

-**Responsibility**-Young person accepts and takes personal responsibility.

-**Restraint**-Young person believes it is important not to be sexually active or to use alcohol or other drugs.

3. Social Competencies-**Planning and decision making**-Young person knows how to plan ahead and make choices.

-**Interpersonal competence**-Young person has empathy, sensitivity, and friendship skills.

-**Cultural competence**-Young person has knowledge of and comfort with people of different cultural/racial/ethnic backgrounds.

-**Resistance skills**-Young person can resist negative peer pressure and dangerous situations.

-**Peaceful conflict resolution**-Young person seeks to resolve conflict nonviolently.

4. Positive Identity-**Personal power**-Young person feels he or she has control over "things that happen to me."

-**Self-esteem**-Young person reports having a high self-esteem.

-**Sense of purpose**-Young person reports that "my life has a purpose."

-**Positive view of personal future** - Young person is optimistic about her or his personal future

Sesma et al, 2006, p.283-284

Sesma, A., Mannes, M. & Scales, P. (2006) Positive adaptation, resilience, and the Developmental Asset Framework in: Goldstein, S & Brooks, R (Eds) Handbook of Resilience in Children. Springer. USA

Ref: (www.search-institute.org/assets/forty.html)

ADDENDUM 11

EMAIL TO PARENTS

EMAIL TO PARENTS

To All Parents,

I am an Educational Psychology Masters student who is undertaking my thesis within the area of intellectual disability. I am in particular looking at the experiences of the **siblings** of children with an intellectual disability. I hope this research will aid in informing the development of support programs and interventions for siblings.

I am looking for participants who will be willing to be a part of this thesis study. (i.e. the **sibling without** an intellectual disability will be the **participant**)
All participants and families will remain anonymous.
The age of the sibling must be between 8years and 16 years.

The time requirements will be the following:

1. One short meeting with the family if possible
2. One interview with the sibling (+-1 hour)
3. One questionnaire for a parent to complete

All meetings and interviews will be arranged to suit the participants and their families in terms of times and venues (at participants home if appropriate).

If you are interested in and willing to partake in this study, please can you call me on 021-555-5555/ 083 555 5555 or e-mail me at xxx@sun.ac.za. Please provide a name, surname, child's name and age, and a contact phone number.

Thank you for your consideration in this regard and I hope to hear from you. If you have further questions please feel free to contact me.

Kind Regards
Sarah

ADDENDUM 12

EXCERPT OF OBSERVATION

EXCERPT OF OBSERVATIONS

Excerpt of observations made at the initial 'family' meeting with participant 1 (P1)
and his mother (Mrs X).

March 2007

.... We then spoke in general about the experiences of the family. Mrs X then recounted some of the details and events that occurred during their lives since XX was born. She spoke about support for parents, the difficulties of parenting, the feelings of guilt and many other intimate and detailed events in their lives. P1 was initially reserved. He sat quietly, listened and watched his mother intently as she spoke. I felt he was becoming aware of the significance of his mother's experience. He also appeared to be warming up to the idea of speaking to me, as he began to involve himself in the conversation and make more eye contact with me. At the same time he appeared to be feeling both intrigued with and concerned about some elements of the conversation. He at certain times would earnestly recount facts about 'sister' and her life, and from time to time would say to his mother: "tell her (researcher) about (this) or (that)". At one point in our conversation P1 said to his mother that he hadn't known about some of the events and incidents she was talking about. His quietness, and frequently watchful demeanour, led me to believe that in his hearing some of his mother's accounts, he was experiencing a deeper, different level of understanding for himself, as well as on his mother's behalf.