

THE IMPACT OF DISABILITY ON SIBLINGS OF CHILDREN WITH DISABILITIES

by

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## **DECLARATION**

I declare that **'THE IMPACT OF DISABILITY ON SIBLINGS OF CHILDREN WITH DISABILITIES'** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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SIGNATURE

(Mrs C. Janse van Vuuren)

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DATE

## **SUMMARY**

Sibling relationships are dynamic within any family context and disabilities add a different and even more complex dimension to a family context. In addition, inclusion is a relatively new concept in South Africa, especially as an inclusive society. This means that it is challenging for a family that has children with disabilities to live and function in the greater society as children with disabilities have specialised needs and expectations. However, siblings of children with disabilities have their own needs and expectations as participating individuals within a family context and within society; therefore it is of relevance to be fully aware of their personal views, perceptions, understanding and challenges they are confronted with. The primary aim of this study was to gain a rich and in-depth understanding of how the disabilities of a child could impact on a non-disabled sibling. With the above mentioned taken into account, siblings of children with disabilities are faced with an array of unique challenges that may change as the siblings develop, therefore, this study focused on siblings who are in their middle childhood phase (six to twelve years old). Qualitative research methods were applied to gain an in-depth understanding of the children's experiences and views. The review of the literature provided the theoretical framework against which the qualitative research was conducted. Semi-structured interviews were constructed from the comprehensive literature review. Observations and documents were also used as research instruments to collect descriptive and supportive data. Interpretations were made from the data collected. The literature review exposed and recognised variances regarding sibling experiences about living with children with disabilities. Five information rich participants were interviewed. The findings of this empirical investigation revealed that not all the siblings identified the same experiences as shared experiences of being siblings to children with disabilities. Therefore, it is recommended that the challenges these siblings are faced with should be taken into account since it has been revealed that there seems to be a need to support these siblings and their families. The whole family is a nested system interacting with each other, within the family system and with other systems beyond the family system, including the wider community and society. Thus, siblings need regular, understandable and updated information as they grow up, regarding the challenges the families are faced with, pertaining to the disabilities experienced, within this nested system.

## **KEY WORDS**

Siblings, Disabilities, Middle childhood, Inclusive education, Inclusive society.

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# CHAPTER 1

## INTRODUCTORY ORIENTATION, STATEMENT OF THE PROBLEM, AIM OF THE STUDY AND CLARIFICATION OF CONCEPTS

### 1.1 INTRODUCTION

#### *Holding hands*

*Brother and Sister, together as friends,  
ready to face whatever life sends.  
Joy and laughter or tears and strife.  
Holding hands tightly as we dance through life.*

*Suzie Huitt (Brother and Sister poems)*

The poem above emphasises that siblings share a special bond. Levitt and Cici-Gokaltun (2011:473) view sibling relationships as being unique. "The companionship that siblings experience in childhood provides a foundation for what is one of the few *lifelong relationships*' that most individuals will experience" (McHale, Dariotis & Kauh 2003:258). Furthermore, Goldenberg and Goldenberg (2000:74) view sibling relationships as a representation of a child's first peer group and within this relationship a child develops interpersonal skills and patterns of negotiation, cooperation, competition, mutual support and attachment to friends which may be of influence later in school or workplace relationships. In addition, Littleton and Miell (2005:97) are of the opinion that children's interactions with other children are important contexts for development and through these interactions, children develop and build their social understanding. Consciously or unconsciously, siblings are utilised to learn about oneself throughout life (Berg-Cross 2000:419).

Sibling relationships can be complex, especially if age-gaps, birth-order, gender, culture, family structure and family dynamics are taken into account. Whiteman, Bernard and Jensen (2011:7) contribute to this notion by viewing brothers and sisters as individuals that are able to influence one another directly as well as indirectly through their impact on the family system. Whiteman, Bernard and Jensen (2011:7) elaborate further by stating that it is imperative to note that sibling relationships are embedded within a larger family system. Furthermore, according to Negron (2007:5), families are faced with numerous challenges throughout their lives that will have an impact on the entire family and one of these challenges could be that there is a child with a disability within the family.

The Integrated National Disability Strategy White Paper (1997:10) reveals that children with disabilities experience both fear and exclusion from a very early age and that separation from family, friends and peers are common. The Integrated National Disability Strategy White Paper (1997:10) also acknowledges that these exclusions affect other non-disabled siblings, the survival of the family as a unit and the meaningful development of the child with disabilities. Olkin (1999:109) contributes with the following statement: "Siblings are an important resource for the child with disabilities. They carry a credibility that parents don't always have, because they know what it is like to be a child".

## **1.2 BACKGROUND TO THE PROBLEM**

Schools, families, and other social institutions are being simultaneously restructured by external events in our society and the traditional family function has been eroded by poverty, divorce, gender, as well as the new world of work (Morse, Paul & Rosselli-Kostoryz 1997:17). In addition, according to Lansdowne (2009:92) the UN Convention on the Rights of the Child (UNCRC) endorses the family as the natural environment for children and recognises the need for children to grow up within a family in "an atmosphere of happiness, love and understanding" and it also emphasises that families should provide all the necessary assistance to enable children to fulfil their responsibilities.

The family could be seen as a complex adaptive system where family members exchange information with others in their environment and the ensuing adjustment in their behaviour is evident (Graff, Neely-Barnes & Smith 2008:267). The authors elaborate further by stating that one family member could influence the other family members through a network of connections and because interactions are nonlinear, small events can have large effects and similarly large events can have small effects. Furthermore, living with a disability may make a family feel isolated and alone, especially if social encounters reinforce the view that a person with disabilities is someone who is not worthy (Burke 2007:23). Burke (2007:23) also notes that families may acknowledge differences as a welcome challenge, confirming individuality and a sense of being special. However, Burke (2007:23) mentions that there might also be significant obstacles to conquer. Therefore, Bronfenbrenner's ecological model seems appropriate for this enquiry, since parents invest a great deal of time, effort, attention and energy in a child with disabilities, which may influence the time dedicated to the other siblings in a family. Furthermore, these demands and challenges may have either a positive or negative impact on the family dynamics and functioning level of each family member (Aksoy & Yildirim 2008:770; Giallo & Gavidia-Payne 2006:937; Dodd 2004:41; Opperman & Alant 2003:441; Strohm 2001:48).

Bronfenbrenner examined contexts on varying degrees of specificity, from microsystems through to mesosystems, exosystems and macrosystems (Pellegrini & Bjorklund 1998:28). The authors

elaborate further by stating that according to Bronfenbrenner, children's behaviour could be explained in contexts and that these contextual experiences, in turn, could affect the children's subsequent development. In addition, Huston and Ripke (2006:10) contribute by affirming that according to Bronfenbrenner and Morris (1998), middle childhood is acknowledged as a developmental time when children's worlds expand beyond family to schools, peers, activities outside school hours, and adults outside the family and that the larger social environment, including public policies affecting parents' employment, income and resources available to children, in turn, influences these experiences. Thus, intervention must be traced through all of these systems to be effective (Morse, Paul & Rosselli-Kostoryz 1997:153). Improved information about children is essential in a society where children's roles as consumers and citizens are being taken increasingly seriously in the economy, in law and in social policy (Scott 2008:103).

### **1.2.1 Awareness of the problem**

The initial awareness of the research problem developed out of the researcher's interaction with and exposure to a sibling pair where a sibling to a child with disabilities exists within the researcher's extended family. A family member has two daughters, one who is seven years old and one who is ten years old. The younger daughter experiences intellectual, emotional and behavioural disabilities. This is due to the early closure of her mid-brain as well as the underdevelopment of her pituitary gland. Together with this, she was diagnosed with Addison's disease, which is a challenging auto-immune disease. Her older sibling has to continuously adapt to her family environment on an emotional, cognitive, behavioural and functional level. The whole family has to adapt quite frequently as the child with disabilities develops and grows. The family experiences financial constraints on a daily basis, because of immense amounts of money invested in medical and therapeutic services. The sibling has been exposed to a vast amount of positive and negative experiences and she has had to deal with a great deal of emotions in a very short time.

On a more personal level, the researcher's own son was born with a congenital laryngeal web, together with subglottic stenosis. Put differently, this means that he has a very soft, high-pitched voice and a smaller than usual trachea, which may or may not improve with multiple intensive and invasive surgeries. In dealing with disabilities within families, it led the researcher to enquire about disabilities and the impact it may or may not have on siblings of children with disabilities.

### **1.2.2 The need to conduct research**

Siblings may come from the same family, but recognizing and respecting differences is important to each one's uniqueness, including disability experienced within the family. Children with disabilities have been included in families and in the outside world. However, this inclusion could

have an impact on the family, especially on other children who may not fully comprehend the feelings and reactions they experience. According to Olkin (1999:109), siblings of children with disabilities could develop strong identifications with disability issues in the same way as siblings that grow up to have a strong identification with one another. Olkin (1999:109) continues by stating that siblings are exposed to the same misconceptions, stereotypes, stigmas and discrimination due to the disability, just as the child with the actual disabilities. Burke (2004:45) contributes by mentioning that siblings who have brothers or sisters with disabilities may experience an increased sense of being “left out” which often goes unrecognised within the family and that professional help would be a valuable form of intervention. Furthermore, Olkin (1999:109) is of the opinion that siblings are routinely overlooked during the treatment of children with disabilities and that they are not consulted about treatment decisions and they may not even be informed of these decisions made. Olkin (1999:109) continues by stating that siblings are excluded from discussions and not consulted about their opinions.

Most of the research that has been done on the phenomena may still be relevant, but the modern family may encounter additional challenges and be under more pressure, whether it be family structure and dynamics, financial pressure, time management and inclusive education settings. Disability and sibling relationships have been extensively explored from an international perspective. However, the research based on siblings of children with disabilities within the South African context appears to be limited. Therefore, a need to concentrate on siblings of children with disabilities and the identification of their experiences motivates this study. In addition, it is imperative to consider the recent paradigm shift to inclusive education, which has an inclusive society at its core. Furthermore, according to Olkin (1999:109), siblings require varying information and assistance as they develop. Olkin (1999:109) elaborates further by explaining that when children enter school, they will be exposed to more negative attitudes, comments and behaviours towards the child with disabilities. Sroufe, Cooper and DeHart (1992:440) contribute by viewing middle childhood as a time when children start to broaden their self-understandings to include not just simple categorical aspects of the self, but broader mental and emotional aspects as well. In addition, Sroufe *et al* (1992:440) continue by stating that children in their middle childhood become increasingly aware of the self within a social context and able to assess personal abilities by making comparisons with peers. In conclusion, research into middle childhood has shown very clearly that it is not an uneventful time and that a great amount of emotional and social development takes during this developmental phase (Sroufe *et al* 1992:438). This study intends to contribute to the existing knowledge of family dynamics. In doing so, it hopes to create a greater awareness and deeper understanding of siblings of children with disabilities.

### **1.2.3 Exporation of the research field**

The literature review relevant to this study has been structured into four main sections with related subsections:

#### **1.2.3.1 *Understanding sibling relationships***

Siblings may fight and have arguments, but they can be highly protective of their brother or sister (Littleton & Miell 2005:114). Sibling relationships seem to be dynamic in nature. Most people are in need of companionship and this special friendship usually starts with siblings and the relationship they share, which can be uplifting, loving, caring and positive and also frustrating and negative. Levine (2002:164) contributes by stating that all sibling relationships contain a measure of jealousy, anger, fear, worry, embarrassment, and even hatred on the worst days along with love, admiration, respect and friendship. Levine (2002:164) elaborates further by viewing a sibling relationship as a relationship where important aspects such as sharing, empathy, worry and love could be learnt. Furthermore, Deater-Deckard, Dunn and Lussier (2002) describe sibling relationships as “emotionally ambivalent—a typical pair of siblings will be warm as well as conflicted at times. For many it is the combination of intense positive and negative emotions that make the sibling relationship so salient” (p.572).

#### **1.2.3.2 *The needs and expectations of children with disabilities***

Reichman, Corman and Noonan (2008:680) consider children with disabilities as children who seem to have a variety of educational, physical, emotional, psychological as well as social child care needs. Reichman *et al* (2008:680) elaborate further by stating that early intervention programmes for needs, specialised education programmes or facilities may be necessary and that adaptations may have to be made as the child grows older and these adaptations may be vital on a continuous basis. In addition, according to Norway and Jenkins (2007:108), children with some of the most complex needs may not receive the support that they require, although these specialist services play an important role in these children’s lives. Furthermore, Harris (2008:361) mentions that children with disabilities have a variety of needs resulting from their disability.

The Integrated National Disability Strategy White Paper (1997:5) concludes by stating that there is not enough usable or reliable information regarding the nature and prevalence of disability in South Africa. In addition, it mentions that statistics are an unreliable source for information because of different definitions of disability, negative traditional attitudes towards people with disabilities and poor service infrastructure for people with disabilities in underdeveloped areas.

### **1.2.3.3 The impact of disability on siblings of children with disabilities**

#### *a) The paradigm shift towards inclusive education and society*

A child is born and grows up within a family and this family is the first and foremost inclusive setting a child is exposed to. Within this family setting children are faced with a variety of challenges, whether it includes relationships with parents, siblings, extended family, friends, neighbours or other people within society. In this regard, Heiman (2002:161) mentions that families that have children with special needs face both the normal pressure and tensions of family life, and, in addition, adjustment to the presence of the child with disabilities. Furthermore, families do not live, exist and function in isolation, but within a society and this is where families become exposed to, challenged by and open to inclusion and exclusion on different levels, whether it may be discrimination, race, poverty, HIV status, disability or any other aspects that may deviate from the “norm” that was set by society at any given time. Therefore, the following statement by Badza, Chakuchichi and Chimedza (2008:53) seems relevant and applicable to this study: “It is not the child with disabilities that needs to be adapted or changed, but the school environment and its supporting systems so that the school recognizes and is able to serve the diversity in the society in which it exists. Children with disabilities are part of that diversity. The concept of ‘inclusion’ is therefore broader and includes inclusive societies, communities, families and schools”.

#### *b) Bronfenbrenner's bio-ecological model*

Gargiulo and Kilgo (2005:61) mention that when a child with disabilities becomes a member of the family, whether through birth, adoption, or later onset of the disability, the ecology of the family changes and the entire family often must make adjustments. This first inclusive setting, the family, is thus confronted with a variety of challenges. Negron (2007:6) mentions that according to Turnbull, Turnbull, Erwin and Soodak (2006), families are viewed as interactive systems and what happens to one member of the family affects the entire family. In addition, Negron (2007:6) mentions that each subsystem (marital, parental, sibling and extended family) plays a critical role in the functioning of the daily task accomplishments of the family. Furthermore, according to Goeke and Ritchey (2011:179), the parental view of a disability sets the stage for how children will interpret sibling behaviour. The extent of an individual's needs cannot be adequately addressed without consideration of the broader contexts about where he or she lives (Goeke & Ritchey (2011:179). Therefore, according to Pellegrini and Bjorklund (1998:30), Bronfenbrenner's model defines contexts most inclusively. These systems and related content are discussed in further detail in Chapter 2 (2.4.2).

#### *c) The needs and expectations of siblings of children with disabilities*

Dodd (2004:43) propounds that siblings of children with disabilities need information, appropriate to their needs, about the disability in the family and these needs may change over time as the child grows older and is able to understand more. Dodd (2004:43) expresses further that it could be

difficult and challenging for a parent to meet the needs of the non-disabled sibling as they may be too busy with the child who has additional needs and they even may want to protect the other children and conceal information from them, which could make these children feel excluded. In addition, according to Kresak, Gallagher and Rhodes (2009:144) siblings are excluded from information and from the search for answers concerning the disability. In addition, Kresak *et al* (2009:144) state that parents could help siblings to become better adjusted to living with a child with disabilities through inclusion and by providing them with information regarding the disability experienced by their brother or sister. Furthermore, according to Negron (2007:8) siblings of children with disabilities have informational needs including information about the condition of their brother or sister with a disability, on how to manage their sibling's behaviour, on how to teach their siblings new skills or even how to interact with their sibling in more appropriate ways. Negron (2007:8) continues by stating that siblings require guidance and support in understanding their roles and responsibilities, their own feelings and emotions as well as guidance and support in understanding how relationships with their own friends and family may be affected and how to deal with these challenges.

Naylor and Prescott (2004:202) researched sibling relationships between siblings and their brothers and sisters with disabilities and their findings revealed that the siblings desired time to themselves and they wanted opportunities to meet children who are in similar situations. In addition, Naylor and Prescott (2004:203) also revealed through their research that the siblings' perceptions of their lives were positive as well as negative at times and that the siblings felt that the brothers and sisters with disabilities received more attention. Furthermore, through their research Naylor and Prescott (2004:203) found that it was difficult to encourage the siblings to focus on their own needs rather than their brother or sister's needs. In addition, according to Strohm (2001:50) parents recognised that siblings have individual reactions and responses to the disabled sibling, and that even siblings within the same family reacted differently. The research also revealed that parents expressed concern for their non-disabled children, but they felt that there is a difference between recognising the non-disabled sibling's needs and responding to their feelings and this the parents found difficult to do, because it was more emotionally demanding on the already weary parents.

Naylor and Prescott (2004:202) identified through their research that siblings of children with disabilities may be exposed to difficulties that include:

- not being able to watch television in peace
- having to do things for their brother or sister with disabilities
- managing distractions when doing homework and even
- experiencing feelings of depression because the brother or sister with disabilities may not be able to do all the activities that they are able to do.



Conversely, Conway and Meyer (2008:116) explain that according to Orsmond and Seltzer (2007), siblings who are encouraged to challenge, enquire and contribute to their brother or sister with disabilities' life, may develop confidence and self-assurance, throughout the sibling relationship.

*d) The role of the family where there is a child with disabilities within the family*

According to Seligman and Darling (2007:29-30), a child with a disability could alter the family dynamics and the identity of the family by financial means, or by the restriction of social and recreational activities that could be pursued, and even regarding career decisions. In addition, Seligman and Darling (2007:29-30) state that parents are sometimes required to do more at home with their child with disabilities than the family system is able to effectively manage. Seligman and Darling (2007:29-30) also mention that the family could experience too much responsibility, which leads to stress, confusion, tension, conflict and depression. Furthermore, according to Reichman, Corman and Noonan (2008:680), living with a child with disabilities is a unique experience for everyone involved. Reichman *et al* (2008:680), elaborate further by affirming that living with a child with disabilities could improve and heighten family members' awareness of their inner-strength as well as their feelings of togetherness and it could serve as an encouragement to reach out to and connect with community groups. However, Reichman *et al* (2008:680) also mention that financial costs, physical and emotional demands as well as time management and other complexities could negatively influence the family dynamics.

Children exist as part of a family with their other significant family members and the togetherness that a family experiences makes the family a unit. The way the family as a unit manages difficulties experienced by the individual family members, can either enhance, improve and strengthen the family structure and dynamics or it can have a negative effect on all the members concerned. In addition, Gargiulo and Kilgo (2005:61) found through their research that families of young children with disabilities are exposed to some unique challenges that include the following:

- expensive medical treatment, surgery or hospitalization
- substantial expenses and financial burdens beyond medical costs, incurred by needs such as special food and equipment
- transportation problems, especially if the child requires special equipment
- babysitting requirements for other children
- time away from employment to ensure that the child is taken to various consultations and treatment appointments
- constant fatigue, lack of sleep and little or no time to meet the needs of other family members.

Therefore, understanding the needs of children and families could better enable practitioners to provide appropriate support (Harris 2008:359). Furthermore, an understanding of what works in supporting children with disabilities and their families is increasingly important as the population of children with disabilities increases and in addition, there appears to be a limited amount of research into what services are effective in meeting the needs of children with disabilities and their families (Harris 2008:366).

#### **1.2.3.4 *The need to support siblings of children with disabilities***

Parents may not always provide the correct information regarding the disability or understand what the sibling may experience; therefore, support may be useful for the non-disabled sibling. The support can be in any form including teachers, therapists, friends, support groups, peers and other professional people. Giallo and Gavidia-Payne (2006:946) contribute by viewing family contexts as important determinants when faced with sibling adjustment difficulties and intervention strategies should be available when support is provided to the whole family.

Strohm (2001:50) established a sibling project for siblings of people with disabilities, called 'The Sibling Project' in April 1999 in Australia. This pilot project was established to develop and coordinate resources and services for siblings of people with disabilities and chronic illness (Strohm 2001:50). Furthermore, according to Strohm (2001:50), the parents and the siblings felt that it is important and beneficial to be in contact with other siblings in the same situation. "Adult siblings wished they had had contact with other siblings as children" (Strohm 2001:50). Naylor and Prescott (2004:204) developed a sibling support group, in the North-West of England, for school-aged siblings of children with disabilities. According to Naylor and Prescott (2004:204), the siblings of the children with disabilities as well as their parents viewed the sibling support group as "positive" and as an "opportunity for siblings to be able to mix with other children with similar experiences or in similar situations". Furthermore, Naylor and Prescott (2004:204) mention the following positive outcomes of the support group for the siblings of children with disabilities:

- increased self-esteem
- increased quality of life
- increased social interaction
- increased coping strategies within the family situation
- increased understanding of disability issues.

In conclusion, according to Gargiulo and Kilgo (2005:82), networking with other families could expose families to opportunities to solve problems and it could also provide opportunities for enrichment. In addition, Gargiulo and Kilgo (2005:82), also note that families may require access, and in the end, benefit from access to resources and information designed specifically for them.

### **1.3 DELIMITATIONS OF THE STUDY**

The study was limited to siblings of children with disabilities. The siblings of children with disabilities were further limited to siblings who find themselves in their middle childhood phase. This means inclusion of children between the ages of six and twelve years and exclusion of children outside these age perimeters for detailed investigation of the research problem. Due to the research sites (in a major city in Gauteng), these children reside in urban settings. Consequently children from rural settings were excluded. The children should have a good command of Afrikaans or English. Gender, race, and socio-economical status were not taken into account.

### **1.4 STATEMENT OF THE PROBLEM**

What is the impact of disability on siblings of children with disabilities?

### **1.5 AIMS OF THE STUDY**

#### **1.5.1 Primary aim**

The primary aim of this study is to gain a rich and in-depth understanding of how the disabilities of a child could impact on a non-disabled sibling.

#### **1.5.2 Specific aims**

##### ***1.5.2.1 To answer the following research questions***

- How do siblings of children with disabilities describe and view themselves as individuals?
- What challenges do siblings of children with disabilities encounter in their lives?
- Is there a need to support siblings of children with disabilities?

##### ***1.5.2.2 To conduct a literature study***

The research questions were explored by means of a comprehensive literature study to gain background knowledge regarding the following aspects:

- Understanding sibling relationships
- The needs and expectations of children with disabilities
- The impact of disability on siblings of children with disabilities
  - The paradigm shift towards inclusive education and society
  - Bronfenbrenner's bio-ecological model
  - The needs and expectations of siblings of children with disabilities
  - The role of the family where there is a child with disabilities within the family

- The need to support siblings of children with disabilities

### **1.5.2.3 To conduct an empirical study**

The research questions were explored further through the use and analysis of qualitative interviews, observations and documents. The methodological orientation of this study was interpretive theory, since interpretive theory as low-level or as hoc theories could be used to explain a given set of data (D. Krüger).

## **1.6 EXPLANATION OF TERMS**

### **Siblings**

Siblings can be biological, through one parent (step siblings) or both parents (full siblings), adoptive, or step-siblings (Walker, Allen & Connidis 2004:176). Furthermore, according to Walker *et al* (2004:176), siblings know one another intimately, as they are linked by childhood experiences unlikely to be known by others.

### **Middle childhood**

Middle childhood (i.e. children who are between the ages of six and twelve years) is a phase that is generally identified as children's first significant entrance into institutions beyond the family (Cooper, Coll, Bartko, Davis & Chatman 2005:5). In addition, Cooper *et al* (2005:5) mention that this is the time when children begin school, a vital setting for learning how to participate in their broader communities, both as children and later as adults. Children and families increasingly navigate across multiple contexts, such as home, work, school, peers, sports, or religious activities (Cooper, Coll, Bartko, Davis & Chatman 2005:5).

### **Inclusion**

Inclusion is a political and social struggle which foregrounds differences and identity and which involves whole-setting and practitioner reform (Clough & Nutbrown 2006:2). Clough and Nutbrown (2006:3) views inclusion as the drive towards maximal participation in and minimal exclusion from formative settings, from schools and from society. Understanding difference and how children think about difference is an important aspect when developing inclusive practices and policies (Clough & Nutbrown 2006:4).

### **Disability**

A person with a disability is limited in one or more functional activity and this may be in seeing, hearing, communicating, moving, learning or other intellectual and emotional activities (SAHRC 2002:9). In addition it is mentioned in the report by the SAHRC (2002:9) that the disability may be permanent, recurring or transitory and it may be sensory, physical, cognitive or psychological.

However, it is also mentioned that people who have very different disabilities experience similar barriers and discrimination in society.

The extent and experience of disability is largely determined by how much the person's environment prevents her or him from taking part in community life on an equal level with others (SAHRC 2002:9). The report also alludes to the fact that disability is imposed by society when a person with disabilities is denied access to full economic and social participation.

*The Education White Paper Six: Special Needs Education- Building an Inclusive Education and Training System* (2010:6) identifies the following categories of disability: Multiple disabilities, deaf, hard of hearing, blind, partially sighted, deaf/blind, cerebral palsy, specific learning disability, behavioural disorders, mild or moderate intellectual disability, severe intellectual disability, physical disability, autistic spectrum disorders, epilepsy, attention deficit disorder, with or without hyperactivity.

### **The social model of disability**

The social model of disability suggests that the collective disadvantages of people with disabilities is due to a complex form of institutional discrimination and this discrimination is fundamental to the manner in which a society thinks and operates (Integrated National Disability Strategy White Paper of 1997). The White Paper furthermore acknowledges that the social model is based on the belief that the circumstances of people with disabilities and the discrimination they face are a socially created phenomenon and have little to do with the disabilities people experience. In addition, according to the White Paper, the disability rights movement believes that the 'cure' to the 'problem' of disability lies in restructuring society.

The social model emphasises two things: the shortcomings of society in respect of disability, and the abilities and capabilities of people with disabilities themselves (Integrated National Disability Strategy White Paper of 1997). The White Paper continues by stating that the social model implies that the reconstruction and development of society involves the recognition of and intention to address the developmental needs of people with disabilities within a framework of inclusive development. Furthermore, according to the Integrated National Disability Strategy White Paper of 1997, nation building, where all citizens participate in a single economy, is only able to take place if people with disabilities are included in the process.

## **Barriers to learning**

Barriers to learning refer to difficulties that arise within the education system as a whole, the learning site and / or within the learner himself or herself which prevents access to learning and development for learners (The Education White Paper 6: Special Needs Education- Building an Inclusive Education and Training System, 2010:6).

### **1.7 RESEARCH DESIGN**

The nature of this research is qualitative. Merriam (2009:05) defines qualitative research as the understanding of people and how they interpret their experiences, how they construct their worlds and what meaning they assign to their experiences. Furthermore, according to Goodwin and Goodwin (1996:108), the qualitative orientation acknowledges that multiple realities exist and that flexible and evolving strategies, such as personal and focused attention on the views of participants themselves, are required to determine these realities and their associated meanings. Therefore, understanding is acquired by analysing the many contexts of the participants and by narrating participants' meanings for these situations and events.

In the search for shared meaning in context, interpretative theory emphasises the detailed explanation of texts. Therefore, since this research study focuses on the impact of disability on siblings of children with disabilities, the research approach is interpretative. Gomm (2009:178) describes an interpretative approach as a qualitative approach with the objective of understanding how people interpret their experiences and the meaning that events and situations have for the people who experience them. In addition, Pellegrini and Bjorklund (1998:108) mention that according to Walsh, Tobin and Graue (1993), interpretive research has the following three defining attributes:

- conducting research in natural settings
- having questions and methods emerge during the process of field work
- stressing the participants' perspectives

Still concerned with subjective meaning, the review of the literature provided the theoretical framework against which the qualitative research was conducted, thus adding constructivism as the research paradigm (knowledge is constructed through mental activity by perceiving and interpreting realities). According to Hatch and Barclay-McLaughlin (2005:504), individually constructed realities seem to be legitimate objects of investigation and the voices of individuals provide depth and breadth to the understanding of experiences. The empirical study consists of information rich participants who were interviewed and observed. Siblings of children with disabilities were interviewed to gain an in-depth understanding of how the disabilities of a child could impact on a non-disabled sibling.

Semi-structured interviews were constructed from the comprehensive literature review, which is discussed in Chapter 2. Furthermore, the “Three Wishes” Projective technique as a form of questioning was incorporated into the interviews. The interviews produced data in the form of word-for-word transcripts, notes and summaries of the interviews. The interviews were recorded on audiotape and transcribed to facilitate qualitative content analysis. Observations and documents were also used as research instruments to collect data and content. The observations were recorded as descriptive notes and as field notes, as a result of active listening and observing participants. Documents can be used as evaluation data or as supportive data.

Qualitative research methods were applied to familiarise the researcher with various perceptions, beliefs and feelings of people. In order to achieve this, the establishment of rapport (a trust relationship) was critical regarding the successful interviewing of participants (Hennink, Hutter & Bailey 2011:63). Hennink *et al* (2011:63) elaborate further by explaining that the closeness and intimacy in the relationship between the researcher and the participant demands careful consideration of the ethical principle of ‘doing no harm’, by securely maintaining the acquired information and by making the data anonymous. Anderson and Morrow (2011:40) contribute by acknowledging that children should be assured from the start of a research project that they are free to withdraw at any stage, stop an interview or not to answer a question. In addition, Anderson and Morrow (2011:40) mention that researchers should be alert to signs of distress or reluctance. It is imperative that informed consent was obtained from the parents and thereafter assent from the child (siblings of children with disabilities), both verbally and in written format. Copies of informed consent and assent letters were distributed to parents and participants. Furthermore, Einarsdottir (2007:76) observes that informed consent provides participants with enough information in a language that is understandable to them to allow them to make an informed decision about participation. Einarsdottir (2007:76) elaborates further that it is vital that participants should know and comprehend the purpose of the research, what the research involves, what is going to happen and for how long, how the results are used and what the consequences are of taking part. In addition, participants were informed that they have the right to withdraw from the study at any time and they would be given time to consider their participation in this study. Participants were given time to ask questions before they participated as well as during participation. Participants were ensured that participation was voluntary and that they had free choice to partake in this study.

Ethical issues, including informed consent, confidentiality, protection and relationships are fundamental in research. However, in research with children these principles are even more important (Einarsdottir 2007:76). Therefore, participants were assured of confidentiality and anonymity and the researcher was aware of cues and signals of discomfort indicated by the participants and therefore, acted accordingly, to lessen the discomfort experienced. The research

process, risks involved and confidentiality were explained to participants in a language that was understood by them.

In conclusion, emotional responses of participants were acknowledged and the interviews and research process was discontinued if necessary and as indicated by participants. Children must be understood as having their own set of interests that may complement or oppose the interests of others (e.g. other children, parents, teachers or researchers), thus the researcher took cognisance of the complex social situations in which child participants find themselves (Freeman & Mathison 2009:70). In this regard, the researcher represented the views of the participants in an ethically sound manner and the researcher applied active listening skills when working with the participants. Furthermore, the researcher respected the children's views and opinions. Graue and Walsh (1998:62) contribute with the following words: "being ethical requires honesty, to ourselves as well as to others".

Inductive thinking was used when content was analysed, since the research process involves open-ended responses in the interviewing process. The content was analysed and organised according to themes or patterns and categories that emerged from the collected data. Thereafter, the researcher was able to make interpretations and summarise findings that reflect upon the participants' knowledge, experiences and life stories. Details regarding the data collection and analysis will be discussed in greater detail in Chapter 3.

## **1.8 RESEARCH PLAN**

The dissertation consists of five chapters:

### **1.8.1 Chapter One**

Chapter 1 contains the introduction, which provides an overview of the research problem.

### **1.8.2 Chapter Two**

Chapter 2 documents the literature study which explores sibling relationships, the needs and expectations of children with disabilities, the impact of disability on siblings of children with disabilities (the paradigm shift towards inclusive education and society, Bronfenbrenner's bio-ecological model, the needs and expectations of siblings of children with disabilities as well as the role of the family where there is a child with disabilities within the family) and the need to support siblings of children with disabilities.



### **1.8.3 Chapter Three**

Chapter three provides detailed information regarding the research plan, method, design, sample selection, data collection and analysis, as well as ethical considerations.

### **1.8.4 Chapter Four**

Chapter four contains the detailed empirical research pertaining to this study.

### **1.8.5 Chapter Five**

Chapter five contains findings, conclusions and recommendations for further research resulting from this study.

## **1.9 CONCLUSION**

We live in a fast-paced world and terms such as “the Z-generation” explain children who experience life on a different technological and global level. However, it is increasingly important to remember that children are allowed to be children, whether they are children with disabilities or children without disabilities. Any child is a gift and adults should treat children as a gift and not a given. Therefore respect, love, acknowledgement and care should flow from every adult’s encounters with all children. Children are unique and individual human beings who grow up seeking a path to follow. Adults, parents, professionals and any other significant people in children’s lives need to listen to their voices and hear them speak up about their needs in the desire to create the best life for them.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

“Children need people in order to become human... It is primarily through observing, playing, and working with others older and younger than himself that the child discovers both what he can do and who he can become—that he develops both his ability and his identity... Hence to relegate children to a world of their own is to deprive them of their humanity, and ourselves as well”.

*Urie Bronfenbrenner (1973: Preface:xvii) (Urie Bronfenbrenner Quotes)*

This quote from Bronfenbrenner acknowledges that children are individuals who are entitled to their specialised needs at any given time in their lives. Deiner (1999:5) contributes by stating the following: “All children are unique, yet they have much in common. Like adults, they all have strengths as well as limitations. All children have specialised needs some of the time...When children have diverse needs, whether temporary or permanent, there is danger of considering only how different those needs make them”. Therefore, as adults, researchers and educators, there is an obligation to continuously observe, identify, do research about children as well as assist them in order to acknowledge and meet their personalised needs, as children form the cornerstone of our society. Little attention has been given to siblings of children with disabilities, and how the disabilities impact on their lives, especially from a South African perspective, as previously mentioned in Chapter 1. This chapter includes and acknowledges contributions made by previous research, both international and national research, which serves as a starting point for this research.

#### **2.2 UNDERSTANDING SIBLING RELATIONSHIPS**

A sibling relationship is viewed, according to Cicirelli (1995:4) as an interdependency of children in a family who either (1) share some degree of common biological origin (full siblings or half siblings); (2) share a relationship defined legally (stepsiblings or adoptive siblings); or (3) share some degree of commitment or socialisation to the norms of sibling roles in a particular culture (fictive siblings).

McHale, Dariotis and Kauh (2003:258) state that most children grow up in households that include one or more siblings and this companionship that siblings experience in childhood can provide a foundation for one of the few “lifelong relationships” that most individuals may experience. Levitt and Cici-Gokaltun (2011:473) contribute by viewing a sibling relationship as a relationship that begins in early childhood and that continues throughout most of the individual’s lifetime. According

to Dunn (2002:224) some siblings show affection, interest, cooperation and support in a majority of their interactions, whereas other siblings show hostility, irritation and aggressive behaviour. Likewise, Levitt and Cici-Gokaltun (2011:473) identify and characterise sibling relationships as being both close and conflicted, although these relationships vary in the degree of closeness and conflict. Edwards, Mauthner and Hadfield (2005:504) reveal similar findings regarding sibling closeness and sibling division, as well as Kim, McHale, Crouter and Osgood (2007:960); Dunn (2007:310) and Dunn, Slomkowski and Beardsall (1994:315).

In addition, McHale, Dariotis and Kauh (2003:258) find that siblings could affect one another through their everyday interactions when they serve as models, teachers and social partners as well as through indirect influences where they impact on roles and relationship dynamics in the larger family system. Kretschmer and Pike (2009:581) contribute by ascertaining that siblings in childhood are important role players in a child's day-to-day well-being, simply by the vast quantity of time they spend with one another.

Berg-Cross (2000:407) reveals that during middle childhood, siblings often spend more time with one another than with anyone else, since they are the most available playmates, although they are not considered as the preferred friends. McHale *et al* (2003:241) views middle childhood as a time of considerable change in children's social competencies and interpersonal relationships.

Tomonari and Feiler (2003:278) contribute by stating that the social skills learned through peer and family relationships during middle childhood as well as these children's increasing ability to participate in meaningful interpersonal communication, provide a necessary foundation for the challenges of adolescence. In addition, Sroufe, Cooper and De Hart (1992:457) view middle childhood as a developmental stage where children could be influenced by older and younger siblings, since relationships change during this stage. Furthermore, Sroufe *et al* (1992:466) are of the opinion that as part of a child's social network, sibling relationships influence development in middle childhood and these are influenced by the child's other relationships. Tomonari and Feiler (2003:278) state that the primary developmental task of middle childhood could be called *integration*, both in terms of development within the individual and of the individual within the social context.

### **2.3 THE NEEDS AND EXPECTATIONS OF CHILDREN WITH DISABILITIES**

It is understandable that children with disabilities have individual needs, as acknowledged and reflected by the Children's Act 38 of 2005 (ss 6(2)(d) and (f)) as well as (ss 11(1)(a-d); (2)(a-c) and (3)). Burke (2008:19) is of the opinion that the needs of children with disabilities should not only be governed by medical descriptions, but since these children should primarily be seen as children, their needs will be the same as other children's needs, as well as unique and specialised.

Furthermore, according to Charlesworth (2000:56), children with special needs or disabilities may need special help because of conditions that make their developmental patterns different from other children. However, they should primarily be seen as children first and secondly viewed as individuals that require certain special needs (Charlesworth 2000:56).

“Many children with disabilities are active contributors to their families, classrooms and communities. However, children with disabilities are often “handicapped” unnecessarily or unfairly restricted—not by their disabilities, but by the ways the disability is interpreted by the social environments where they live, learn and relate. How parents view the disability sets the stage for how children interpret sibling behaviour. The extent of an individual’s needs cannot adequately be assessed without consideration of the broader contexts in where he or she lives” (Goeke & Ritchey 2011:179). According to Opperman and Alant (2003:441) the family needs to adapt in order to accommodate the physical, caring and intervention needs experienced by a child with disabilities. Furthermore, Opperman and Alant (2003:441) also mention that children with severe disabilities need a greater degree of care-giving since they may exhibit more disruptive behaviour. Connors and Stalker (2003:20) identified several themes regarding the experiences, needs and expectations of children with disabilities. They include the following:

- taunting and bullying experienced in mainstream and special schools
- the experience of being treated as “normal” within the family may or may not be empowering
- the need for services to take a holistic family and social model approach
- the importance to children of being asked for their opinion and being listened to
- the fact that children’s views can be different from those of their parents.

In conclusion, Middleton (1999:03) states that children with disabilities grow up having to make sense of the world around them in the context of their difficulties experienced, and yet non-disabled parents and other adults may not be in a position to interpret, understand or advise. Middleton (1999:03) continues by adding that non-disabled adults cannot really “know” what it is like to see the world as their child sees it, or to hear how they hear or, similarly, what it is like to have an unruly tongue. This may lead to feelings of isolation, fear, being misunderstood as well as a constant need to explain themselves (Middleton 1999:03).

## **2.4 THE IMPACT OF DISABILITY ON SIBLINGS OF CHILDREN WITH DISABILITIES**

“All individuals have personality characteristics that can be strengths or make families more vulnerable to the stresses of raising children with diverse abilities. Adding a child to any family increases stress and when this child is diagnosed with a disability, an already stressful time is magnified” (Deiner 1999:51).

#### **2.4.1 The paradigm shift towards inclusive education and society**

“Working towards inclusion is a far more complex process than assembling even the most challenging of jigsaw puzzles” (Pirrie & Head 2007:25). South Africa experienced a challenge when a shift from special education to inclusive education was proposed, given the history of special education in South Africa.

The developments within a democratic South Africa constituted a paradigm shift, and within the South African context (Naicker 2005:244), this shift meant the following as stated in the *Education White Paper Six on Special Needs Education: Building an Inclusive Education and Training System* (Department of Education, 2001): “It is essential to acknowledge that the learners who are most vulnerable to barriers to learning and exclusion in South Africa are those who have historically been termed ‘learners with special education needs’, i.e. learners with disabilities and impairments” (Department of Education, 2001, p.18).

According to Naicker (2005:244), the focus is not merely on disability, but rather on all vulnerable children, including over-age learners, children in prison, learners who experience language barriers, or barriers such as the attitudes of others, lack of parental recognition and poverty. Furthermore, Lutfiyya (1995:118) argues that inclusive settings are those in which individuals with and without disabilities participate together as equal members. Therefore, Deiner (1999:30) views the purpose of inclusion as helping all children gain interactional skills that will be valuable throughout life, as well as to provide appropriate care and education for all.

International and national trends regarding disability have experienced change, which has influenced the shift towards inclusive education in South Africa. These paradigm shifts centred mainly on the move from the medical model of disability to a social model of disability (Naicker 1999:12; Burke 2008:13). Therefore, these two paradigms will be discussed in some detail:

- The medical model of disability

The medical model is, according to Swart and Pettipher (2005:05), a model of diagnosis and treatment and it focuses on pathology and sickness. Burke (2008:13) contributes by stating that the medical model views the person with disability as someone needing treatment, and this is not always a true reflection of disability. Swart and Pettipher (2005:05), argue that the medical model of disability has its place. However, Swart and Pettipher (2005:05), also mention that the medical model is not tremendously helpful when one is working in the social sciences where the barriers are not only within the person, but can also be found in the community.

- The social model of disability

According to Burke (2008:14), the social model indicates that environmental factors can contribute to disability and consequently the context of disability extends beyond the individual. Burke (2008:14) is of the opinion that the social model encourages change within the social setting so that situational, emotional or physical barriers to access do not disadvantage children with disabilities. Seligman and Darling (2007:33) contribute by stating that young children with disabilities do not live in isolation and that the family should be considered as a dynamic, interdependent unit that lives in a broader context of their immediate community and beyond.

Bronfenbrenner's social ecological model could be applied to families of children with disabilities, since, according to Shaffer (2008:97), Bronfenbrenner's ecological systems theory adopts a contextual worldview. Berry (1995:379) contributes by stating that Bronfenbrenner's (1979) social ecological model focuses on the developing person, the environment, and the evolving interaction between the person and the environment. Berry (1995:379) continues by acknowledging Bronfenbrenner's (1986) inclusion of the family and external influences on the individual's development. In addition, Shaffer (2008:97) elaborates by stating that according to Bronfenbrenner, people are influenced by many environmental contexts, ranging from home settings to the wider society in which they live. However, Shaffer (2008:97) also mentions that Bronfenbrenner views children as active biological beings who change as they mature and who's influenced behaviours in turn can influence the environments that influence their development.

Connors and Stalker (2003:25) state that according to Dowling and Dolan (2001), the social model perspective highlights the way in which the child with the impairment as well as the whole family can be "disabled" by unequal opportunities and social barriers. In addition, Naicker (2005:250) acknowledges that there is a clear link between education and society and that South Africans are trying to create conditions in schools that will result in an inclusive society.

It is assumed that social life is played out within a framework of relationships within which people seek inclusion and "belongingness". Relationships necessarily include people, but they also have boundaries that, by definition, exclude other people. These boundaries could be challenged or crossed (Abrams, Hogg & Marques 2005:1). According to Engelbrecht (1999:4), the movement towards inclusive education is understood by means of a contextual analysis and synthesis and in addition, the values, understanding and actions of individual people can be understood within the social context in which they occur. Therefore, since schools are influenced by political, economic

and social developments, they do not function in isolation, but are rather shaped by the developments and changes in society (Swart & Pettipher 2005:04).

Inclusion may also have an impact on siblings of children with disabilities regarding the influence inclusion has on relationship patterns within the family as well as with peers and other significant people outside the home. Inclusion may also impact on siblings' interactions with peers, especially during the middle childhood phase, since, according to Harold and Hay (2005:5), peer relationships increase in importance during middle childhood (Tomonari & Feiler 2003:278). Therefore, Bronfenbrenner's paradigm and model of ecological development seems appropriate and relevant to this study, because Charlesworth (2000:24) explains that Bronfenbrenner stresses the importance of viewing children in all their roles in all areas of their environment.

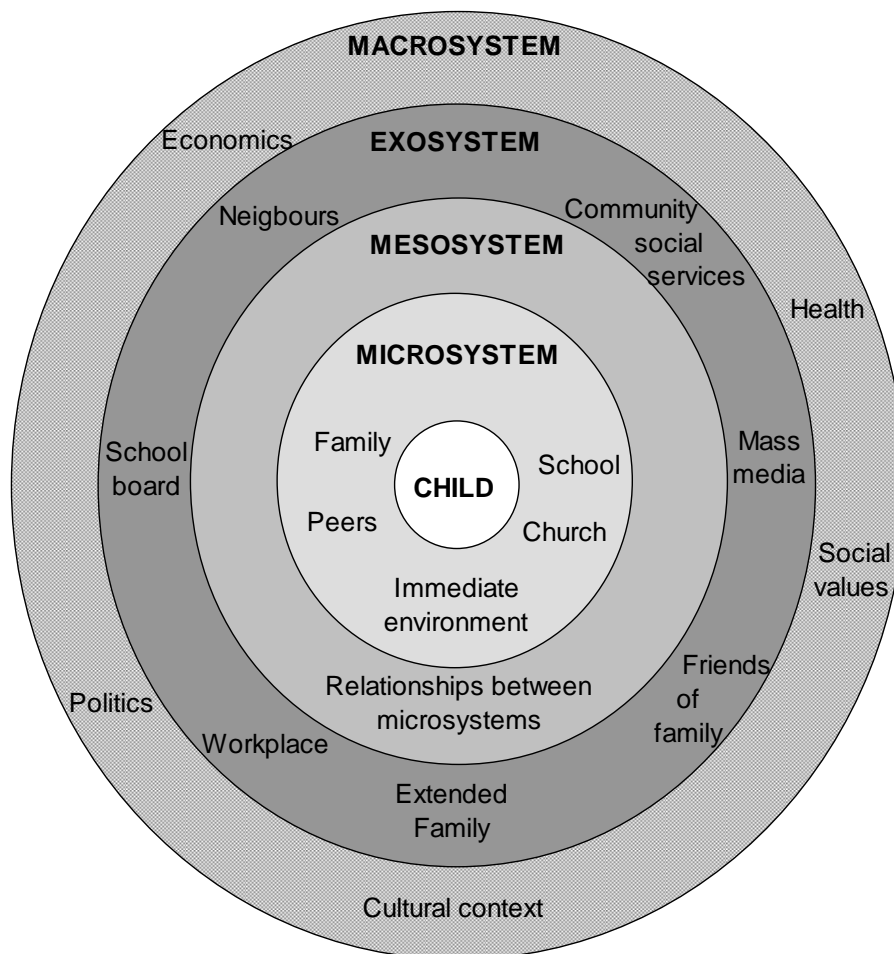
#### **2.4.2 Bronfenbrenner's Ecological Model**

The daily lives of children may be altered significantly when they grow up with siblings with disabilities, and these experiences may have important consequences for the children's well-being and development (McHale & Gamble 1989:421). In addition, Sroufe, Cooper and De Hart (1996:44) are of the opinion that human development takes place in contexts such as the culture into which the child is born; the community the child is part of; the child's home, family, peer group and school as well as the surrounding socio-economic climate. Sroufe *et al* (1996:44) continue by stating that all of these contexts influence development, usually in complex and interlocking ways. Furthermore, Bronfenbrenner proposes an ecological model and a bio-ecological model of human development that is multi-dimensional, as stated in Swart and Pettipher (2005:10).

Bronfenbrenner's models of human development suggests that there are layers of interacting systems that result in change, growth and development on the physical, biological, psychological, social and cultural levels (Swart & Pettipher 2005:10). According to Sroufe *et al* (1996:44), Bronfenbrenner proposes a model of concentric rings where each ring influences all the rings inside it. Furthermore, as seen in Figure 2.1, the child with his or her own biological make-up is at the centre of the rings (Sroufe *et al* 1996:44). The microsystem surrounds the child, which includes their relationship to the home, school, neighbourhood, peer group, and church (Charlesworth 2000:24). Sroufe *et al* (1996:44) describe this microsystem as the child's immediate environment that contains all the people, settings and physical objects with which the child has direct contact. The mesosystem surrounds the microsystem and this system, as stated in Swart and Pettipher (2005:11) refers to the relationships that develop and exist between these microsystems. The mesosystem includes interactions and relationships between and among home, school, neighbourhood, church and peer group (Charlesworth 2000:24). The exosystem, according to Bronfenbrenner (1979:237), contains one or more settings, that may not involve the child as an active participant, but in this system events occur that indirectly influence or is influenced by the

immediate environment of the child. The exosystem includes additional influences such as the local school board, the local government, mass media and local industry (Charlesworth 2000:24).

The macrosystem refers to the attitudes, beliefs, values and ideologies of a given society and culture, which may impact or be influenced by any of the other mentioned systems (Swart & Pettipher 2005:12). In addition, Berry (1995:380) indicates that Bronfenbrenner identified another system, the chronosystem, which examines changes over time within the person and the environment as well as dynamic relations between the two.



**FIGURE 2.1: Bronfenbrenner's ecological model**

Source: Adapted from Charlesworth (2000:24); Sroufe, Cooper & DeHart (1996:44); Swart & Pettipher (2005:11).

Bronfenbrenner introduced a model where the child is an active participant in his or her own development and interacts with their environments (Swart & Pettipher 2005:12). Furthermore, according to Darling (2007:204), the child actively shapes his or her own environments, evoking responses from them, and reacting to them. Therefore, Berry (1995:379) believes that social



ecology serves as a framework for viewing difficult issues involving individual and family adjustment to societal change, including adjustments faced by individuals who have developmental disabilities and their families.

Seligman and Darling (2007:33) propose that the ecological paradigm suggests that a change in any part of the system affects sub-parts of the system, and this creates a need for the system to adapt. Furthermore, according to Seligman and Darling (2007:34), social policies can affect families of children with disabilities. In addition, the authors suggest that it is becoming increasingly important to study and examine the family within the context of the larger social, economic, and political realities, rather than just focusing on studying the child or the dynamics that occur within the family.

Children as individuals live within a family and they are surrounded by family members, friends and peers within a school environment, which is within a community and within a certain society. This means that each one within these systems influences the others and vice versa. Therefore, to conclude, the following statement by Bronfenbrenner (1992:248) seems appropriate: "We have to rebuild the connections between the home, the school, the work place, the community, and the neighbourhood. We have to recognise the fact that families are not self-sufficient. We have to provide recognition and resources at the concrete level, at the local community level..."

#### **2.4.3 The needs and expectations of siblings of children with disabilities**

Siblings adjust to having a brother or sister with a disability in diverse ways (Giallo & Gavidia-Payne 2006:937). Strohm (2001:49) views siblings of people with special needs as people who often grow up in a stressful environment and often without the cognitive and coping mechanisms to deal with their experiences. Strohm (2001:49) is also of the opinion that services that are available to siblings of children with disabilities should have a more preventative approach to provide these children with the necessary skills to deal with their experiences in order to grow up as emotionally strong and capable people. Giallo and Gavidia-Payne (2006:944) contribute by stating that their study revealed that positive family experiences may be important when promoting positive adjustment outcomes for siblings, rather than their own experiences of stress and, in addition, the researchers found that parental stress seemed to have been a strong predictor of sibling adjustment difficulty. Likewise, Aksoy and Yildirim (2008:776) found through their research, that children did not experience their sibling's disability as a barrier in their secure, warm and safe family environment.

Deiner (1999:54) views siblings of children with disabilities as people who may have additional needs. Deiner (1999:54) explains that siblings of children with disabilities need information and they want to know what is going on and that parents, in an effort to "protect" them, often do not tell

them very much. Deiner (1999:54) elaborates further by stating that the limited or poor information adds to the siblings' confusion. For example, if the child wears a hearing aid, siblings need to know what it is for, how it works and what it does and does not do to aid hearing (Deiner 1999:54). Deiner (1999:54) concludes that siblings of children with disabilities need specific information about whether the disability is transmittable, how to talk to their friends about it, how to relate effectively to their sibling and what the family expectations are for their future role with their brother or sister. Furthermore, the special care children with disabilities often require means that many parents must devote extra time, attention, and family resources to these children, possibly at the expense of the interests of other non-disabled siblings in the family and in turn, such differential treatment may lead to feelings of rivalry, jealousy, or hostility by non-disabled brothers and sisters (McHale & Harris 1992:83). McGoldrick and Watson (2011:153) contribute by stating that siblings become especially stressed when parents expect them to be preoccupied with the needs of the children with disabilities or to treat them as "normal".

Connors and Stalker (2003:118) reveal through their research that most siblings described their brother or sister with disabilities in both 'ordinary' and in general, positive terms and that none of their research participants saw their own position, as siblings of children with disabilities, as 'tragic'. Connors and Stalker (2003:118) also found, through their research, that most of the siblings worried about their brothers or sisters with disabilities and some children seemed to have a high-level of on-going anxiety about their brother or sister's well-being.

Strohm (2001:49) lists the following specific concerns that siblings may have, which were found to be mentionable as expressed by authors, parents and siblings:

- a life-long and ever-changing need for information about the disability;
- over-identification with the child who experiences disability and a fear of having or developing the condition themselves;
- feelings of guilt about having caused the disability or "survivor" guilt;
- pressure to be the "good" child, and wanting to protect parents from further distress;
- a perceived pressure to achieve academically or in sports in order to make up for the limitations of the child with disabilities;
- feelings of resentment when the child who experiences disabilities receives more attention or is allowed to behave in ways they are not;
- guilt over typical sibling conflicts (internal aggression);
- embarrassment about their sibling's appearance or behaviour;
- shame about the negative feelings they may experience;
- increased responsibilities and care-giving demands;
- concerns about their own future; and
- feelings of loss and isolation.

Deiner (2005:123) suggests that siblings need to be supported in finding the appropriate words and concepts to share with their friends. According to McHale and Gamble (1989:421), siblings of children with disabilities may fail to benefit from experiences outside the home, for example, time spent with their peers, which normally facilitates the development of cognitive, social, and affective competencies, due to extra time demands for family responsibilities, but these responsibilities may also encourage maturity as well as enhance feelings of self-esteem and competence within the child (McHale & Gamble 1989:421). Giallo and Gavidia-Payne (2006:945) contribute by mentioning that family activities may serve as a resilience factor for siblings of children with disabilities, which allows them to regularly share positive experiences, receive social support and deal with problems. In addition, according to Kresak, Gallagher and Rhodes (2009:152), it is important to understand that the needs of siblings vary, depending on their age and the age of the child with disabilities. Furthermore, simple explanations can ease feelings of resentment and jealousy (Seligman & Darling 2007:237).

In conclusion, Miller (1996), as quoted in Dodd (2004:43), views siblings as very important role players in family life, and accordingly, it is essential that they are under no obligation to take on roles beyond their age and ability. Additionally, there is potential to improve the experiences of many siblings so that they will have been offered 'unusual opportunities as well as unusual problems'.

#### **2.4.4 The role of the family where there is a child with disabilities within the family**

A family is a "dynamic web of multiple perspectives, multiple roles, and multiple influences" (Martin & Cole 1993:186). Harris (2008:360) declares that when there are children with disabilities within the family, it is important for the parents to have accurate information regarding the disabilities in order to understand and adjust to the child's disability. Furthermore, according to Harris (2008:360), families of children with disabilities also have a significant need for material support that can include finance, transport and housing that will help meet the practical problems when caring for some children with disabilities. In addition, Giallo and Gavidia-Payne (2006:938) mention that families of children with disabilities, who may experience difficult life circumstances on a regular basis, may be challenged regarding their management of stressful circumstances.

According to McGoldrick and Watson (2011:153) small families tend to experience more pressure when there are children with disabilities within the family, because there are fewer siblings to share the responsibilities. Depression can be a serious problem in families of children with disabilities, and it often goes undiagnosed (Seligman & Darling 2007:203). In addition, Seligman and Darling (2007:212) state that the families of children with severe disabilities require extensive day-to-day support in order to meet their basic needs, as parents attend to their child's medical, educational and therapy needs, and these activities can be isolating and exhausting.

Martin and Cole (1993:194) suggest that the demands of caring for children with disabilities, especially regarding development, may require a “pooling” of family resources and this may lead to a more cohesive relationship among family members.

A study conducted by Giallo and Gavidia-Payne (2006:948), reveals that siblings from families who use effective communication and problem-solving were reported to have better adjustment outcomes than siblings from families who use less effective communication and problem-solving strategies. This study also revealed that some families may need support to develop and maintain regular and predictable family routines as well as support in sharing positive family experiences. In another study, Dyson (1996:285) found that the family placed increased emphasis upon personal growth of the family members when challenged with the presence of a child with learning disabilities. Furthermore, Dyson’s study (1996:285) reveals that parents experienced a high level of parental stress as well as negative experiences and conversely, the non-disabled siblings’ experiences were more positive. In addition, Dyson’s study (1996:285) suggests that according to their results, there is a need to support families of children with learning disabilities. Burke (2008:49) reveals that some of the parents in his research study reported that they treated all their children in the family the same, despite the fact that the child with disabilities had more and greater needs than his or her siblings. Furthermore, Burke (2008:53) found that some families reported that they experienced even more closeness than before as a family, as a result of helping each other with the caring needs of the children with disabilities. In addition, Burke (2008:53) concluded that caring for children with disabilities polarised families as either staying together and strengthening the relationship, or as separating to start a new life.

Connors and Stalker (2003:44) found through their research, that even though children with disabilities and their families have regular contact with their extended family, most parents feel unsupported by them, and according to the researchers this may be due to various reasons that include the extended families being unsure of how to treat children with disabilities and that they experienced the children as being “different”. On the other hand, Connors and Stalker (2003:44) alluded that some relatives provided short breaks for the children from their parents, creating an alternative space for development for both the able siblings and the siblings with disabilities.

Strohm (2001:49) identifies that there is a lifelong concern and need to support siblings of people with disabilities, but in order to support the siblings; the parents need to be supported as well. Parents also need to be able to communicate with each other, and share their fears, resentment and confusion in an accepting and understanding environment (Strohm 2001:49). In addition, Strohm (2001:49) indicates that families need to work together and they need to develop skills to improve their feelings of competence and self-worth. Across a family’s life span, family members

need to adapt, negotiate and communicate (Seligman & Darling 2007:191). Although this serves to be true for all families, it is essential for families in which there is a child with a disability or a chronic illness (Seligman & Darling 2007:191).

## **2.5 THE NEED TO SUPPORT SIBLINGS OF CHILDREN WITH DISABILITIES**

Many families rear a child with a disability at home with little additional support and that help is usually only available when the family experiences a crisis (Dodd 2004:43). Dodd (2004:43) continues by stating that the needs of siblings are often neglected even though families receive supportive services. Dodd (2004:43) elaborates further by viewing siblings as people who have very important roles to play in family life, however Dodd (2004:43) is of the opinion that it is essential that siblings should not be obliged to take on roles beyond their age and ability. Furthermore, according to Lamorey (1999:87), parents reported that they can become overwhelmed by the needs of a child with a disability or a life-threatening disease, and that it is not unlikely that siblings would also experience a sense of being similarly overwhelmed, especially when the siblings have few tools with which to understand the nature of meanings of disability and disease. Lamorey (1999:87) elaborates further by stating that siblings often overachieve and excel on an academic or sporting level in order to compensate for the shortcomings and limitations of the child with disabilities and that they tend to take over certain household duties such as cooking, cleaning and caretaking. In addition, siblings of children with disabilities may feel that they have to put their sibling's needs first; this may originate as a predisposition to early maturity in these children. Their parents may be concerned that they have to grow up too quickly (Lamorey 1999:87). However, the positive aspect of this is that they are often described as very responsible and sensitive to the needs and feelings of others (Hewitt-Taylor 2008:48).

Deiner (1999:54) is of the opinion that a sibling's sense of obligation for a brother or sister with disabilities can be a major concern and may require professional counselling. In addition, Deiner (1999:54) mentions that siblings do not expect the situation to be "fixed", and that they do, however, need a safe time and place to express their feelings and to be accepted. Deiner (1999:54) elaborates further by viewing siblings as people who may need specific support in developing their own identity and that they may need the opportunity to talk with other siblings of children with disabilities and if a support group is available, the children may want to be a part of it. Furthermore, siblings need to be asked directly about their perceptions (Deiner 1999:54). Therefore, according to Lamorey (1999:88) communication between home and school can contribute positively to the sibling's healthy development, especially regarding social and academic background. Often, siblings whose identities and interpersonal relationships have revolved around their role as caretaker within the family need to have the support of teachers and other professionals regarding the development of healthy peer relationships, discovering their own

personal needs and interests as well as balancing academic accomplishments with personal and social development (Lamorey 1999:88).

In contrast, Stoneman (2009:283) argues that there is no consensus in the researched literature concerning siblings' need for support. Stoneman (2009:283) elaborates further by adding that there is no supporting notion that all siblings of children with intellectual and related disabilities need interventions or therapies. However, Stoneman (2009:283) concluded that individual children or certain sibling pairs might need or benefit from individually tailored interventions.

Dodd (2004:43) on the other hand, expresses that siblings may need the opportunity to share their experiences, worries and concerns with other children in similar circumstances in an understanding and non-threatening environment in order to develop greater self-esteem and ways of dealing with problems that arise, hence the researcher's focus on sibling support groups. In addition, Dodd (2004:43) lists the following as benefits for siblings who may attend these groups:

- meeting with others in a similar position;
- sharing feelings, emotions and ideas about coping with difficult situations and responsibilities;
- sibling support groups that usually offer a mixture of recreation, socialisation, discussion, activities and games and they are designed to be fun as well as supportive.

According to Burke (2008:119), group sessions enable the exchange of ideas and issues such as mixed feelings about having a brother or sister with disabilities, or being bullied at school, which could be shared with others who understand. However Burke (2008:119) added that not everyone wanted to share their family experiences, but the overall feeling of the group sessions were positive as the participants felt understood "without explanation". Furthermore, Burke (2008:124) expresses that membership of a group was not always easily achieved, but through talking about their brother or sister with disabilities in a structured way and through sharing experiences the participants realised that they were not completely alone in their experiences after all, and initial anxieties were overcome. In addition, Connors and Stalker (2003:97) find that some children could discuss their concerns with either or both their parents, but this was not true for all, since some children did not wish to raise these subjects with their parents. Connors and Stalker (2003:97) also mentioned that some children had been told little or nothing about their sibling's disability, while others, who had been given some information, felt that they have not been told enough.

Furthermore, Stoneman (2009:284) views the need for sibling interventions to be dependent on parental perspectives about whether or not their children are developing and behaving in ways that are consistent with family expectations and desires. In contrast, Goeke and Ritchey (2011:178) are of the opinion that positive experiences in schools and community-based settings are especially

important for children with stressful family lives. Therefore, according to Goeke and Ritchey (2011:178), it seems apparent that siblings of children with disabilities whose families have not adapted well might benefit from intervention that provides additional social support. Seligman and Darling (2007:254) affirm that the child with a disability is a total family concern; therefore, they encourage open-communication within the family to help reduce unpleasant circumstances. Seligman and Darling (2007:255) contributes further by stating that reactions from peers may further isolate siblings from their social group and children who feel rejected by their peers and are ignored by their parents are youngsters at risk.

Burke (2008:131) remarks that, according to the social model of disability, it appears that siblings experience a sense of disability by association, as they are perceived by many as different from their friends, and that both siblings and children with disabilities need support to aid their self-expression. Sibling adjustment, well-being, and coping are related to family functioning and when this family functioning does not adapt to the presence of a disability, increased stress can lead to negative results and influences on both parents and siblings (Goeke & Ritchey 2011:169). Furthermore, environments beyond the home that shape sibling roles and interactions that might be used as contexts for intervention remain largely unexplored (Goeke & Ritchey 2011:178). Therefore, it seems important to identify and examine the need to support siblings of children with disabilities, concerning the impact the disability has on their lives, their circumstances and experiences.

## **2.6 CONCLUSION**

Throughout the literature, there are different findings and views pertaining to disability and the impact it may have on siblings of children with disabilities and family functioning. The findings reveal that children's optimum development mostly depends on their developmental contexts and those experiences, whether positive or negative, shared between children, their significant others and their environments within an external environment tend to influence one another in complex and diverse ways. Furthermore, the family environment seems to be the primary environment where developing children are exposed to external challenges. Family members may include parents, brothers and sisters with or without disabilities, and according to the findings, the family is viewed as an interconnected system within which each family member's behavior could influence the behavior of the others and this means that every family member is actively involved in shaping the other family members' relationships and development, over time, within their family as well as within society.

The findings also suggest that sibling relationships tend to be quite dynamic in nature, especially during the middle childhood developmental phase, as these children develop and mature cognitively, emotionally, socially and physically. These changes, in turn, could impact on how

children interact with their environments. Harold and Hay (2005:5) contribute by describing middle childhood as a time when children reach new levels of cognitive, emotional and social functioning that allow them to interpret and engage with their social worlds, as a preparatory step for the challenges that the next years will inevitably bring.

According to the findings, children with disabilities, indeed, have specific and even additional needs and expectations. However, the findings also suggest that the siblings of children with disabilities also seem to have their own needs and expectations. Furthermore, the findings reveal that inclusion and Bronfenbrenner's ecological paradigm suggests that, individual characteristics, the sibling bond, family contexts, peer groups and even the wider community and society play an important role in everyday life. The research regarding Bronfenbrenner's ecological model views the child as an active participant who contributes and influences environmental contexts, thus, according to this ecological model, children with disabilities could have an impact on siblings of children with disabilities. Therefore, as stated in McHale and Gamble (1989:421), studying the daily lives of siblings of children with disabilities may provide insights into issues facing other children and families in contemporary society. In conclusion, Shaffer (2008:97) is of the opinion that development is viewed as the product of a truly dynamic interplay between an active person and an ever-changing "active" environment.

Chapter 3 focuses on the research design and methodology that was used to gain insight into the lives of siblings of children with disabilities.



## **CHAPTER 3**

### **RESEARCH DESIGN**

*“You can design and create, and build the most wonderful place in the world. But it takes people to make the dream a reality.”*

*Walt Disney (Disney, W. Quotes)*

#### **3.1 INTRODUCTION**

This chapter describes the research methodology and design that was utilized to investigate the experiences of siblings of children with disabilities regarding the impact the disabilities have on them as individuals. The purpose of the research is explored as well as the identification of participants. Data collection, data analysis methods and ethical considerations was also discussed in detail.

#### **3.2 PURPOSE OF THE RESEARCH**

The primary aim of this study was to gain a rich and in-depth understanding of how disabilities of a child could impact on a non-disabled sibling.

In order to gain this in-depth understanding, further research questions were posed to the participants which served the purpose, according to Neumark-Sztainer (2008:42) to help advance knowledge in the study by addressing the significant problem. The following specific research questions were utilized in this respect:

- How do siblings of children with disabilities describe and view themselves as individuals?
- What challenges do siblings of children with disabilities encounter in their lives?
- Is there a need to support siblings of children with disabilities?

This study intended to gain valuable insight into the lives of siblings of children with disabilities. Sibling relationships are dynamic within any family context and disabilities add a different and even more complex dimension to a family context.

Inclusion is a relatively new concept in South Africa, especially as an inclusive society. It is challenging for a family that has children with disabilities to live and function in the greater society as children with disabilities have specialised needs and expectations. It should be noted that the siblings of children with disabilities have their own needs and expectations as participating individuals within a family context and within society; therefore it is of relevance to be fully aware of their individual contexts, and the subjective meanings they attribute to their experiences, especially

concerning the implications of having brothers or sisters who experience disabilities. At present, most of the research has focused on parental views and experiences (Kresak, Gallagher & Rhodes 2009:152; Macks & Reeve 2007:1062; McHale & Gamble 1989:421), and the siblings have not yet received the same amount of attention and dedication (Seligman & Darling 2007:182; Connors & Stalker 2003:16).

### **3.3 QUALITATIVE RESEARCH METHOD(S)**

Qualitative research emphasises the complexity of social interactions expressed in daily life, and includes the perspective that the participants are part of these interactions (Marshall & Rossman 2010:02). McMillan and Schumacher (2001:396) contribute by viewing the goal of qualitative research as the understanding of the social phenomena from the participants' perspectives. According to Merriam (2009:14) qualitative research is interested in "the process rather than the outcome of meaning-making" as well as describing how people interpret their experiences.

The qualitative research process involves an inductive approach. Boeije (2010:05) identifies inductive thinking in qualitative research as the exploration of social phenomena in order to "find empirical patterns that can function as the beginning of a theory". In addition, Holloway (1997:91) views inductive reasoning as a shift from the specific to the general, which purports that research commences with the study of a number of individuals or incidents, then moves on to establish generalities that link individuals or incidents to each other. It also includes data collection, data analysis and the generation of theories which may conclude the research actions taken (Holloway 1997:91). Thus, meaningful understanding can emerge from an inductive analysis that uses "open-ended, detailed and descriptive data", which is collected through "direct interactions" with the study and its participants (Patton 2002:172).

### **3.4 RESEARCH DESIGN**

Qualitative research designs are naturalistic in the sense that research takes place in real-world settings and the researcher does not attempt to manipulate the phenomenon of interest and its participants. Observations take place in real-life situations where people are interviewed with open-ended questions under conditions that are comfortable and familiar to them (Patton 2002:39). Marshall and Rossman (2010:04) state that qualitative research involves an interpretive and naturalistic approach to the world where it attempts to interpret phenomena in terms of the meanings people attribute to their interactions with the world. Goodwin and Goodwin (1996:108) propose that according to Walsh, Tobin and Graue (1993) interpretive research can be defined as inclusive research that focuses on the understanding of human meaning in social life. Furthermore, Denzin and Lincoln (2003:11) view interpretive research design and the product thereof as "a complex and reflexive collage or montage where representations are interconnected". Interpretive

qualitative research assumes that reality is socially constructed and that there is no single observable reality, but multiple realities or interpretations of a single event (Merriam 2009:08) (cf. constructivism in 1.7).

Constructivism is added as a research paradigm, since, according to Donald, Lazarus and Lolwana (2002:100), constructivism emphasises that people are seen as active agents in shaping their own development. Furthermore, Donald *et al* (2002:100) identify another related aspect of constructivism, namely that knowledge which is not passively received, but rather actively constructed “through engaging in experiences, activities and discussions” that challenge people, in order to construct meaning from their interactions within their individual contexts in order to build detailed understandings of their world.

Constructivism and the interpretive research paradigm are therefore important and fundamental to this study. Children cannot be seen or understood as passive agents in life, but rather as active agents who derive subjective meaning from their perceived realities and experiences within their own constructed worlds, from which interpretations can be made in order to represent and reflect their knowledge and life stories.

#### **3.4.1 Selection of the sample**

“Qualitative researchers usually work with small samples of people nested in their context and studied in-depth” (Miles & Huberman 1994:27).

Purposeful sampling was utilized for this study. According to Patton (2002:563), purposeful sampling involves the studying of information-rich cases in depth and in detail to understand important circumstances regarding the research. Lodico, Spaulding and Voegtle (2010:134) contribute by viewing the goal of purposeful sampling as a selection of people, places or things that can provide the richest and most detailed information to help answer a research question. Furthermore Ritchie, Lewis and Elam (2003:78) describe the use of purposeful sampling as the selection of participants who have particular features or characteristics which will enable detailed exploration and understanding of the central themes which the researcher wishes to study.

The participants are the siblings to a child with disabilities, therefore, according to Ritchie *et al* (2003:79), a homogenous sample composition was chosen to provide a detailed depiction of a particular phenomenon and this allows for detailed investigation of social processes in a specific context. Furthermore, the participants were interviewed while in their middle childhood developmental stage. McHale, Dariotis and Kauh (2003:246) are of the opinion that according to Piaget (1932), middle childhood is seen as a period during which children become more able to reason and think logically and therefore they do not need to rely on superficial qualities or

characteristics as the basis for their problem solving. During this developmental stage, children learn the values of their society, where integration takes place, both in terms of development within the individual and of the individual within the social context; therefore, middle childhood is important for the development of cognitive skills, personality, motivation and interpersonal relationships (Tomonari & Feiler 2003:278).

Sampling not only focuses on the selection of people to be interviewed or situations to be observed, but also the selection of sites in which such persons or situations can be expected to be found (Flick, Kvale, Angrosino, Barbour, Banks, Gibbs & Rapley 2007:27). The selected site for this study was a major city in Gauteng. In addition, a small population sample of no more than six participants seemed to be best suited for this research study as these cases require in-depth study for better understanding and insight regarding the research topic. Therefore, the number of participants does not compare with a full-scale national population study; however, the sample size serves to generate understanding of the greater population, which is important, as they are representative of other families, especially siblings of children with disabilities who may experience similar scenarios.

#### **3.4.2 Data collection**

Data collection in qualitative research is about learning something about people or things. The focus is on the particular quality of the person or the setting (Mertens 2010:351, McMillan & Schumacher 2001:428). Furthermore, data collection strategies in qualitative research examine words, phrases and statements to determine themes that respond to a research question (Grady 1998:07). Therefore, according to Polkinghorne, (2005:138) the purpose of data collection in qualitative research is to provide evidence of the experiences under investigation and the data is viewed as the basis of the findings.

Patton (2002:04) explains that qualitative findings develop out of three kinds of data collection strategies:

- In-depth, open ended interviews
- Direct observation
- Written documents

Interviews were the main data collection strategy that was used during this study; however, observations and documents were also used, therefore this study made use of multi-method strategies during data collection. These multi-method strategies enabled the researcher to collect and corroborate the data and content from a single strategy with data from other strategies and

thereby the trustworthiness of the information was enhanced (McMillan & Schumacher 2001:428, Goodwin & Goodwin 1996:130).

#### **3.4.2.1 Interviews**

Interviewing provides access to understanding of a person's actions (Seidman 2006:10). Through interviewing, the researcher gathers detailed information regarding the interviewee's thoughts, perceptions, feelings and views (Goodwin & Goodwin 1996:134). Hatch (2002:91) contributes by stating that qualitative interviewing is used to uncover the meaning structures that participants use to organise their experiences and make sense of their worlds.

In-depth interviewing is concerned with the interest and understanding of lived experiences of participants and the meaning they make of that experience (Seidman 2006:09). Open-ended questions establish the territory for exploration while participants are allowed to take any direction they want to take (Seidman 2006:69). Therefore the researcher makes use of in-depth, open ended interviews during this study. Possible open-ended questions were generated by the researcher as a guide during the interviewing process (see Addenda I and J).

In addition, a verbal projective task, namely The Three Wishes, was included in the interview schedule. According to O'Connor and Ammen (1997:45) children may be asked what three wishes they would make if they were given the opportunity. The above-mentioned authors also mention that responses are able to provide some insight into a child's fantasy life as well as a child's unmet needs. Sadock, Sadock and Levin (2007:325) contribute by stating that through the use of verbal projective techniques, such as the Three Wishes technique, "children may impulsively wish for material possessions, while others may reveal longings for distressing circumstances to change". Sadock *et al* (2007:325) also mention that these responses may be starting points for further conversation in the interview.

The interviews were recorded on audio tape and transcribed (see Addendum L), as this allowed for detailed reading in analysis of the relevant content and data (Polkinghorne 2005:142).

#### **3.4.2.2 Observations**

The information from observations consists of detailed descriptions of participants' activities, behaviours, actions and interpersonal interactions that are part of observable human experiences (Patton 2002:04). Furthermore, according to Patton (2002:262) observational data describes and provides detailed information regarding the observed setting, activities that took place in the setting, the people involved and the meanings they attributed to their experiences. Polkinghorne (2005:143) suggests that observations could be used to supplement or clarify information gathered

through participant interviews. Observational data sources also include non-verbal indications, for example facial expressions, body language and behaviour patterns of participants to aid in interpreting their verbal comments (Polkinghorne 2005:143; McMillan & Schumacher 2001:454), therefore any and all relevant observations noted by the researcher during the interview process were added as field notes to the transcriptions of the interviews (see Addendum K).

### **3.4.2.3 Documents**

Document collection is a non-interactive strategy for gathering qualitative information. (McMillan & Schumacher 2001:451). Furthermore, Mertens (2010:373) is of the opinion that documents and records include paper products, such as memos, reports and plans, as well as computer files, tapes (audio and video), and other artefacts. Johnson and Christensen (2009:212) examine document collection further by identifying two types of documents namely personal and official. Johnson and Christensen (2009:212) describe personal documents as anything that is written, photographed or otherwise recorded for private purposes. Some examples of personal documents include letters, diaries, correspondence and pictures. Furthermore, official documents are described as written or recorded by some type of public or private organisation. Some examples of these include newspapers, student records, student work, books and published articles. To conclude, documents and records could be a valuable way to corroborate information from other sources (Lodico, Spaulding & Voegtle 2006:132).

In this research the researcher made use of documentation in the format of a “My own highlights” page that was generated by the researcher (see Addenda G and H). The participants were asked to complete the “My own highlights” page, voluntarily, at home after the initial interview. Thus, the researcher determined that focussing on some artefacts in the setting would add richness to the corpus of data that was gathered (Marshall & Rossman 2010:161). This information has been discussed in a follow-up interview, where the participants were provided an opportunity to discuss and elaborate on their responses with the researcher. According to Scott (2008:103) the interviews confirmed the importance of their own experiences, attitudes, aspirations and achievements for shaping their own destinies.

The following statements and questions were posed in the “My own highlights” page:

- Name your achievements or highlights—think of your school, sport, hobbies or special interests or any other activities.
- Have you ever been a leader? (for example class captain)
- Perhaps you have certificates, school reports, drawings, photos, poems, a diary or something else about yourself that you would like to share with me. If you can think of something, write it down here.

This document collection strategy seems applicable to this research project as the researcher could utilise these documents and records to retrieve the necessary background of the situation and insights into the dynamics of everyday functioning of the research participants (Mertens 2010:373). This document collection strategy also seems applicable to the selected participant sample as the research project focuses on the siblings, who find themselves in their middle childhood phase, to children with disabilities. Cooper, Coll, Bartko, Davis and Chatman (2005:5) contribute by viewing middle childhood as a period that generally marks children's first significant entrance into institutions beyond the family. Cooper *et al* (2005:5) elaborate further by stating that these children and families increasingly navigate across multiple contexts, such as home, work, school, peers, sports, or religious activities.

### **3.4.3 Data analysis**

Data analysis, according to McMillan and Schumacher (2001:461), is viewed as an inductive process where data is organized in various categories and where patterns can be identified among these categories. The above-mentioned authors state that these categories and patterns emerge from the collected data and that an interpretive style is used by most researchers. Goodwin and Goodwin (1996:142) affirm the above mentioned view and contribute by stating that data analysis in qualitative research is closely related to data collection and it occurs throughout data collection as well as afterwards.

McMillan and Schumacher (2001:462) are of the opinion that qualitative data analysis is seen as a relatively systematic process where information is selected, categorized, compared, synthesized and interpreted in order to provide explanations of the phenomenon of interest. Johnson and Christensen (2009:93) contribute by affirming that qualitative data analysis requires coding and searching for relationships and patterns until a holistic picture can emerge (Goodwin & Goodwin 1996:143). Furthermore, coding requires the researcher to organise the information, such as words, phrases, behaviours observed and events recorded, into meaningful categories (Goodwin & Goodwin 1996:144).

An inductive approach was used during the data analysis. The semi-structured interviews (transcribed) were the primary source of data and the observations, and reflective notes such as field notes and other relevant documents were the supportive sources of data. Inductive thinking was used when the content was analysed, since the research process involves open-ended responses in the interviewing process. The content was analysed and organised according to themes or patterns and categories that emerge from the collected data. Thereafter, the data was interpreted and these findings were summarised.

### **3.5 ETHICS**

The ethical practice of research with human participants is a complex and demanding responsibility, thus ethical implications must be taken into account for everyone involved in the process, regardless of the design, context or structure of the research (King & Horrocks 2010:103). Furthermore, according to King (2010:99), ethical considerations and guidelines provide assistance to researchers concerning their work ethic. Thus, qualitative researchers need to be sensitive to ethical principles because of their research topic, face-to-face interactive data collection and interaction with the participants (McMillan & Schumacher 2001:419). To conclude, Macfarlane (2010:26) expresses that “ethics is a bit like jazz. It is about more than simply following the notes on the page. It demands improvisation and an ability to be an interpreter of moods and situations”. In this study therefore, the researcher respected the participants’ views and experiences, since they are the true authors and major role players in their own rich narratives.

#### **3.5.1 Obtaining informed consent and assent**

Informed consent entails informing the research participants about the overall purpose of the investigation and the main features of the research design, as well as of any possible risks and benefits from participation in the research project (Brinkmann & Kvale 2007:266). Informed consent further involves obtaining the voluntary participation of the people involved, and to inform them of their right to withdraw from the study at any time (Rossman & Rallis 2011:74; Brinkmann & Kvale 2007:266). In addition, according to Rossman and Rallis (2011:73) informed consent serves to protect the identities and privacy of participants. Thus, the participants’ names and identifying information were not used in any discussions or written documents about the research (Rossman & Rallis 2011:73).

Gaining the informed consent of participants is crucial for the ethical conduct of research (Rossman & Rallis 2011:73). Therefore, the researcher obtained permission from the principal of the institution consulted (see Addenda A and B). Furthermore, informed consent was also obtained from the parents of the participants involved (see Addenda C and D) and from the participants themselves (see Addendum E and F). The informed consent and assent was obtained both orally and in written format. The participants, the parents as well as the researcher were required to sign the informed consent and assent letters. Parents and participants received their own copies of the informed consent and assent letters. Furthermore, during the informed consent and assent process the researcher provided both written and verbal explanations of the research process including the following aspects:

- The researcher ensured that participants and their parents had been fully informed of the purpose of the study as well as the methods to be used during the research process;



- The participants were informed that they had the right to withdraw from the study at any time without prejudice;
- The participants were given time to ask questions before they participated as well as during participation;
- The participants were ensured that participation is voluntary and that they had free choice to be part of the research project;
- The researcher ensured that participants would remain anonymous by using pseudonyms.
- Possible benefits of this study were discussed and outlined in general and
- The participants were informed of possible risks involved if they participated in the research project.

### **3.5.2 Confidentiality and anonymity**

Confidentiality in qualitative research implies that private data identifying the participants will not be reported (Brinkmann & Kvale 2007:266). Mertens (2010:342) elaborates further by stating that confidentiality means that the privacy of individuals will be protected in that the data they provide will be handled and reported in such a way that they cannot be associated with them personally. Furthermore, according to Gallagher (2009:20) confidentiality is generally achieved by restricting access to data. Thus, the researcher has stored interview transcripts in a locked filing cabinet and in a password-protected or encrypted form on a computer system (Gallagher 2009:20).

According to Cohen, Manion and Morrison (2007:64) the essence of anonymity is that information provided by participants should in no way reveal their identity. The principal means of ensuring anonymity is to omit the names of the participants or any other personal means of identification (Cohen, Manion & Morrison 2007:64; Gallagher 2009:19). This identifiable information of the research study has been replaced with pseudonyms (Gallagher 2009:19) and the researcher has assured the participants of confidentiality and anonymity. Thus, the researcher represented the views of the participants in an ethically sound manner.

The pseudonyms and abbreviations, in Table 3.1, were used during the research process to ensure anonymity:

**TABLE 3.1: Pseudonyms and abbreviations used in the study**

<b>Pseudonym</b>	<b>Abbreviation</b>
Participant 1:A (for first interview)	P1:A
Participant 2:A (for first interview)	P2:A
Participant 3:A (for first interview)	P3:A
Participant 4:A (for first interview)	P4:A
Participant 5:A (for first interview)	P5:A
Participant 1:B (for second interview)	P1:B
Participant 2:B (for second interview)	P2:B
Participant 3:B (for second interview)	P3:B
Participant 4:B (for second interview)	P4:B
Participant 5:B (for second interview)	P5:B

### **3.5.3 Assessing risk of harm**

In qualitative inquiry, the researcher should limit or prevent situations wherein participants experience undue harm during, or as a result of, the research process (Hays & Singh 2011:79). Furthermore, according to King (2010:113) a more personal and in-depth nature of data collection has the ability to guide the conversation into areas that the participant may find distressing. However, King (2010:113) mentions that in face-to face qualitative research, this distress is visible, enabling the researcher to respond to it. Consequently, given the often intense relationship in qualitative research, it is important to constantly monitor participant reactions and to refrain from allowing unnecessary risks for the sake of research (Hays & Singh 2011:79). Hence, the researcher was aware of cues and signals of discomfort indicated by the participants and the researcher acted accordingly to lessen the discomfort experienced. The researcher also acknowledged emotional responses and discontinued the interview and research process if necessary and as indicated by participants.

Since the nature of this research is qualitative and it aims to gain an in-depth understanding of “The impact of disability on siblings of children with disabilities”, the participants were required to explore their personal feelings, experiences and views regarding this topic and voice their opinions in interviews. This means that the interview as a method of collecting data could have provoked some frustration and discomfort in participants as they would have been discussing their experiences. As a result, the level of discomfort experienced by individual participants cannot

always be predicted accurately. The participants may also experience a level of inconvenience, as the interview process requires their personal time and input (although the researcher set a time limit of no more than 30 minutes per interview).

#### **3.5.4 Honesty and integrity in the research process**

According to King (2010:104) a researcher's ethical responsibilities include direct interaction with participants as well as the requirement to act honestly and with integrity throughout the research process. Consequently, there was no deception of any kind in this research project and the researcher did not create false expectations among the participants. In addition, the researcher took precautions against the breach of integrity and there was no falsification, alteration or fabrication of information.

Barbour (2007:85) is of the opinion that a researcher has to cautiously contemplate the following aspects of the research process:

- ethical concerns;
- trying to anticipate the likely impact on research participation;
- being responsible to the wider academic community and society as a whole.

Therefore, the researcher undertook research that could be beneficial to the academic community and to society in general and which could further contribute to previous knowledge on the topic.

#### **3.5.5 Trustworthiness as quality criterion**

"Trustworthiness makes reference to the integrity of someone. A trustworthy person is someone that a person can depend on and have confidence in. To trust someone is to make yourself vulnerable and trust is not to be given lightly" (Hammond & Wellington 2012:147). Furthermore, according to Hammond and Wellington (2012:147) trustworthiness describes the strength of the claims to knowledge the researcher is making. Thus, Toma (2006:412) states that according to Lincoln and Guba (1985) a trustworthy account has the following characteristics:

- confirmability
- credibility
- transferability
- dependability.

##### **3.5.5.1 Confirmability**

Confirmability is generally taken as a measure of how well the findings are supported by the data (Hammond & Wellington 2012:147).

### **3.5.5.2 Credibility**

Credibility is strongly related to confirmability and is enhanced if the researcher has had prolonged engagement with participants (Hammond & Wellington 2012:147). Krefting (1991:215) contributes by viewing credibility as ‘truth-value’ that establishes how confident the researcher is with the truth of the findings based on the research design, participants, and context. Krefting (1991:215) further concludes that in qualitative research, truth-value is obtained from the discovery of human experience as they are lived and perceived by participants.

### **3.5.5.3 Transferability**

Transferability refers to the degree to which the findings of one's investigation is applicable beyond the bounds of the project and which may be undertaken through comparison with other studies (Hammond & Wellington 2012:147).

### **3.5.5.4 Dependability**

Dependability considers the process of data collection, data analysis and theory generation (Hammond & Wellington 2012:147). Consequently, the researcher took the following steps to ensure trustworthiness:

- Participants' views and opinions were respected.
- The researcher protected the interests of the participants and the researcher reported the findings of the research project accurately and truthfully.
- The researcher did not create false expectations among the participants.
- The researcher has preserved and protected research material.
- The researcher has taken precautions against breach of integrity and there have been no falsifications, alterations or fabrication of information, as well as no plagiarism and no piracy of information.
- The researcher undertook research that would possibly be beneficial to the university and to society in general and which would contribute to previous knowledge on the topic.

### **3.6 CONCLUSION**

Understanding how the disability of a child can impact on a sibling is the basis of this study. Therefore, a qualitative research method using an interpretive and constructivist approach to the research design was chosen as it is concerned with people's perspectives and how they interpret their experiences.

The data collection and analysis strategies includes multiple sources of information in order to, as stated in Patton (2002:306), provide a comprehensive perspective to validate and cross-check findings since each source of data has strengths and weaknesses. Ethical considerations, as mentioned and described in section 3.5, were taken into account. Limitations were also taken into account and will be discussed in the ensuing chapters.

The findings of the research in this study are discussed in the next chapter.

## **CHAPTER 4**

### **INTERPRETATION OF DATA AND DISCUSSION OF THE FINDINGS**

*“Every child you encounter is a divine appointment.”*

*Wess Stafford - President of Compassion International*

*(Famous quotes about children)*

#### **4.1 INTRODUCTION**

The aim of this chapter is to present a description and discussion of the findings of the empirical research obtained from the interviews, observations and documents. Participants participated voluntarily in the study and they were interviewed in the language they preferred and felt most comfortable with.

#### **4.2 INTERPRETATION OF DATA**

##### **4.2.1 Data analysis process**

Interpretation is the challenge at the heart of qualitative research (Willig 2012:5). However, without interpretation it is difficult to make sense of data (Willig 2012:5). Furthermore, interpretation refers to the construction of meaning and is concerned with elucidation, explanation, and understanding (Willig 2012:5).

Interviewing was the main means of data collection. Smith and Osborn (2008:59) accentuate the following features of semi-structured interviews:

- facilitation of rapport and empathy
- greater flexibility of coverage
- permits the interview to go into novel areas
- likely production of richer data.

Consequently the interviews were structured to allow flexibility, thus different questions were asked depending on the responses that were given (McBride 2013:52). Therefore, a variety of possible questions and probe questions were asked to ensure clarification and elaboration of what has been shared by the participants. This encouraged a participant to expand on an initial answer to obtain more depth in their responses (King & Horrocks 2010:40). Thus, four participants were interviewed in English and one participant was interviewed in Afrikaans, this means five participants were interviewed in total. Semi-structured one-to-one interviews were designed by the researcher

against the backdrop of the comprehensive literature study that was conducted and discussed in Chapter Two.

The interviews were recorded on audiotape and transcribed, verbatim, into written texts. This assured authenticity of what has been said and revealed during the interview process; therefore language deviations will be present in transcripts. Data saturation was reached when participants voluntarily participated in both the initial semi-structured interviews as well as the follow-up interviews where the document sheet was discussed. Thus after interviewing the participants, the verbatim audio recordings were analysed to determine their experiences, perceptions and understanding of living with a brother or sister with disabilities and the impact it may or may not have on their own lives. Validity and trustworthiness of the findings were achieved by using multiple data collection methods and triangulating of the data collection process (Salkind 2010:1129). This was achieved by combining the five semi-structured interviews with field notes where observations were noted and reflective notes were made by the researcher, as well as the collection and interpretation of documentation.

An interpretive research design and analysis was chosen for this research study as discussed in Chapters 1 and 3. Interpretive studies seek to explore people's experiences and their views or perspectives of these experiences (Gray 2009:36). In addition, interpretive studies are, typically, inductive in nature (Gray 2009:36). Furthermore, according to Terre Blanche, Durrheim and Kelly, (2008:321), good interpretive analysis requires staying close to the data, and to interpret it from a position of empathic understanding. Additionally, Terre Blanche *et al* (2008:321) revealed that the anthropologist Clifford Geertz (1973) described the purpose of interpretive analysis as providing "thick descriptions". This means a thorough description of the characteristics, processes, transactions, and contexts that constitute the phenomenon being studied as well as an account of the researcher's role in constructing this description (Terre Blanche *et al* 2008:321). Therefore, according to Terre Blanche *et al* (2008:321), the purpose of interpretive analysis is not to collect bits and pieces of 'real life', but to place real-life events and phenomena into some kind of perspective. Thus, "interpretive research is to make the strange familiar and the familiar strange" (Terre Blanche *et al* 2008:321). In conclusion, according to Popp-Baier (1999:61), an interpretive data analysis can be understood as a comparative process. This means that the main methodical aspect of interpretation lies in the process of comparison (Popp-Baier 1999:61).

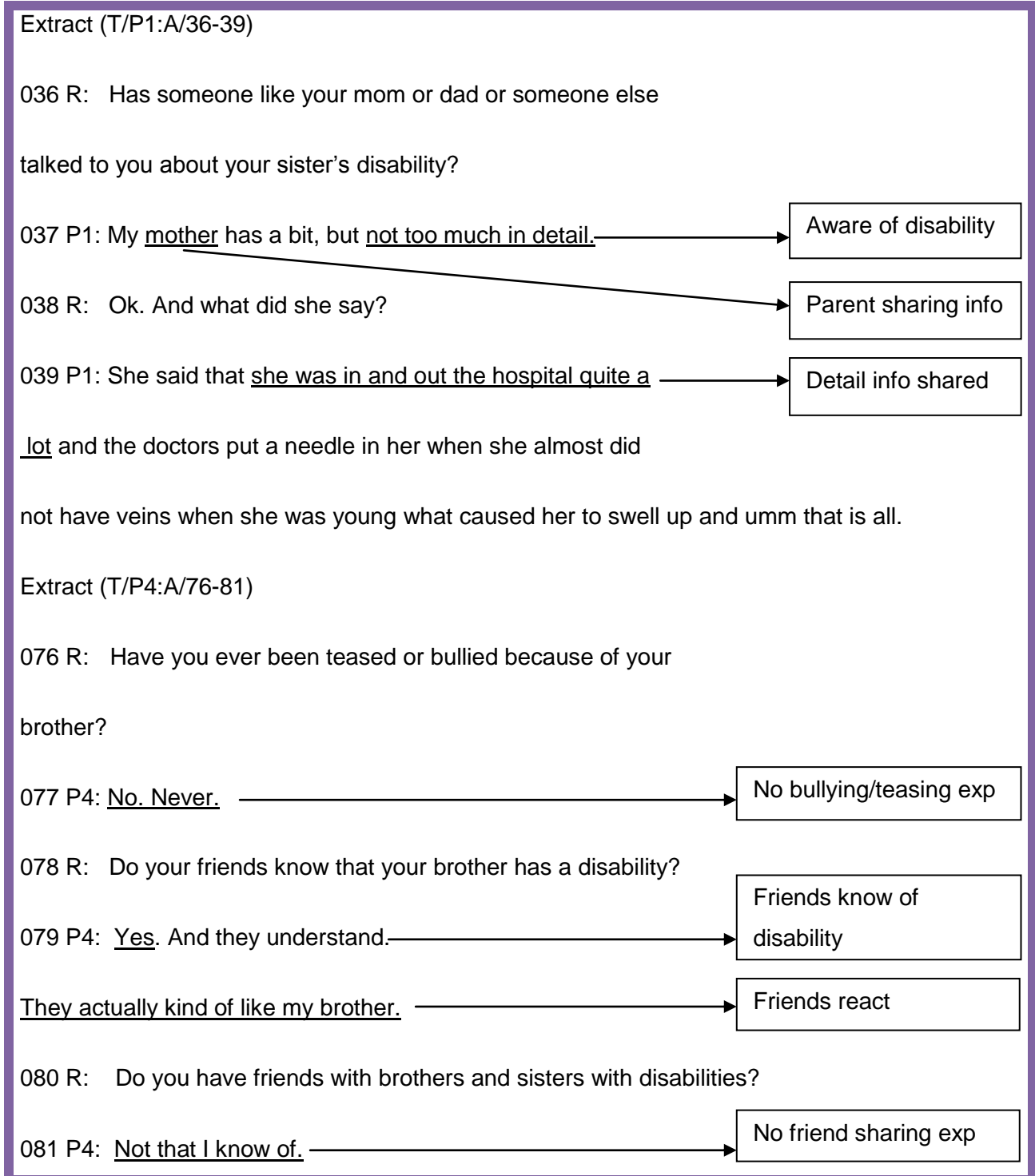
An inductive approach was used in the interpretive study and analysis of the qualitative data (Marlow 2010:217). This means that patterns emerged from the data rather than being developed prior to collection (Marlow 2010:217). Furthermore, the data was organised, classified and edited into an accessible package (Marlow 2010:217). Thus, the qualitative analysis followed an iterative process where the data was revisited regularly as new questions and connections emerged, and

as the overall understanding of the research situation emerged (Hair, (Jr.), Wolfinbarger, Celsi, Money, Samouel & Page 2011:291). Furthermore, an interpretive analytical style of immersion/crystallization was used during data analysis (Terre Blanche *et al* 2008:322). Consequently the researcher became thoroughly familiar with the phenomenon and careful reflections were made, followed by the writing of an intuitive interpretation by the researcher (Terre Blanche *et al* 2008:322). Thus, the data analysis process included the researcher reading and rereading of data collected, creating an opportunity to be immersed in material (i.e. audiotapes, transcripts, field notes and documents collected) and relevant notes were made.

Data analysis consists of segmenting and reassembling the data with the aim of transforming the data into findings (Boeije 2010:94). Furthermore, Boeije (2010:94) mentions that in the data analysis phase of the research project, the data gets sorted, named, categorized and connected, and all those activities entail interpretation. Therefore, analysis began with the collection of data in response to the problem statement, namely, *what is the impact of disability on siblings of children with disabilities?* Consequently the transcripts were read several times to identify themes and categories. The researcher and an independent coder analysed the data and reached consensus regarding the identified themes and categories.

According to Saldaña (2009:3), a code in qualitative analysis usually includes a “word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data”. Accordingly, to codify is to arrange things in a systematic order, to make something part of a system or classification, accordingly, to categorise (Saldaña 2009:8). Coding is the method that enabled the researcher to organise and group similar coded data into categories as they share some characteristics and this resulted in a pattern that emerged. Subsequently, words or phrases were identified and allocated codes to encapsulate pieces of relevant text. The coding method is illustrated through a couple of transcription extracts (T/P1:A/36-39) and (T/P4:A/76-81) in Figure 4.1.





**FIGURE 4.1: The coding method as in transcription extracts**

Categories evolved from the meaning in the coded data and therefore categorising is seen as an interpretive process on the part of the researcher, where the researcher attempted to respect the data and use category labels close to the original language of the participants (Elliot & Timulak 2005:154). Furthermore, according to Elliot and Timulak (2005:154), categorising is seen as an interactive process in which priority is given to the data but understanding is facilitated by previous understanding. In addition, categorising refers to the process of looking for similarities and regularities between established categories (i.e. coded data) (Elliot & Timulak 2005:154). Saldaña (2009:11) contributes by mentioning that some categories may contain clusters of coded data that merit further refinement into subcategories. Hence, the coded data formed the provisional categories and refinement of categories began as coded data units were grouped and compared to expand categorisation.

Thus, major categories were compared with each other and consolidated and this process transcended the “reality” of the data and progress was made toward creating themes (Saldaña 2009:11). Thereafter, relationships between categories were established in order to integrate the data collected. Rossman and Rallis (2003:282) view themes as phrases or sentences that describe more subtle and tacit processes. Furthermore, Rossman and Rallis (2003:284) identify theme generation as “taking analysis to a deeper level”. In addition, according to Rossman and Rallis (2003:284), Van Manen (1990) identified the following four definitions of a theme generated:

- Theme is the experience of focus, of meaning, of point.
- Theme formulation is at best a simplification.
- Themes are not objects one encounters at certain points or moments in a text.
- Theme is the form of capturing the phenomenon one tries to understand.

#### **4.2.2 Data analysis interpretation**

The researcher identified themes and patterns that emerged through data analysis (Bui 2009:180). Themes were generated, resulting from final categories established as seen in Table 4.1.

**TABLE 4.1: The Final Categories subdivided into Themes**

<b>Final Categories</b>	<b>Themes</b>
<b>Independent siblings sharing a home</b>	<ul style="list-style-type: none"><li>• Personal growth and achievements</li><li>• Resilience</li><li>• Sibling relationships</li><li>• Personal space and boundaries</li></ul>
<b>Acceptance of child with disabilities</b>	<ul style="list-style-type: none"><li>• Peer perceptions</li><li>• Awareness of disability</li><li>• Wellbeing wishes / Concerns</li></ul>
<b>Adult / Parental factors</b>	<ul style="list-style-type: none"><li>• Divulgence of needed information</li><li>• Time management and togetherness</li></ul>
<b>Adequate information and support regarding the brother / sister's disability in society and at home</b>	<ul style="list-style-type: none"><li>• Family involvement</li><li>• Being informed</li><li>• Voice emotions and feelings</li></ul>

#### **4.2.2.1 Independent siblings sharing a home**

The five participants revealed through their interviews and their identified highlights that even though they shared a house, parents and a level of personal space with their brothers or sisters with disabilities, they all seemed to be busy and content with their own activities. It should be mentioned that not one of the participants shared their educational environment with their brothers or sisters with disabilities.

The identified themes within this category are discussed in further detail:

##### *a) Personal growth and achievements*

All the participants expressed their own likes, dislikes, most favourite subjects in school and least favourite subjects in school. The participants discussed their special achievements and highlights with pride, ease and confidence. Academic, culultural and sporting activities were discussed, amongst others as reported in the following extracts.

*R: Ok. Tell me a little about yourself. The things you like to do.*

*P1: I like to play cricket, I like playing with my friends. I like playing with my sister. I also like cycling in my estate and I like learning at school.*

*R: That is good and when you grow up what would you like to be or do?*

*P1: I was liking to be a pilot, if I do not go that way I will also like to be a cricket or rugby player(T/P1:A/10-13).*

*R: And what are the things you like to do?*

*P3: I like to play with my toys. I pretend that they can talk. I cut my doll's hair, but it doesn't grow back, so I put in more hair. (smiles) I like to swim with my brothers. Sometimes we play tag in the pool. (T/P3:A/09-10).*

*R: When you grow up - what would you like to be?*

*P3: When I grow up I want to be a vet to help sick animals (T/P3:A/13-14).*

*R: Ok. Let's go through the highlights page. The first question was about any highlights that you want to share with me like sport or activities.*

*P3: I wrote ballet.*

*R: Yes, ballet medals and Spelling Bee and speech. How did those medals make you feel?*

*P3: It makes me feel good because I have been doing ballet since the school started. I never want to quit (T/P3:B/115-118).*

It is evident from the previous and above extracts that siblings live in the same house and come from the same family, their individuality is important. The researcher is of the opinion that this aspect may enhance, encourage and even develop personality traits within a person that is relatively unique. The selected participants are starting to venture into a less secure environment which includes friends, school, community and the wider society.

#### *b) Resilience*

The participants' responses reveal a positive and strong attribute of resilience as they expressed their viewpoints regarding their own experiences within their homes and school environment fairly easily. These children are exposed to a society and environment where people do not always understand individual personal experiences, even though these experiences shape people and their personalities either positively or negatively. Although the participants, as siblings to children with disabilities, are exposed to quite diverse and maybe quite challenging experiences, they did not reveal or express that these were defeating experiences as is seen here:

*R: If you could change one thing in your life, what would it be?*

*P5: Umm (thinking) ... (Silence) NO! (T/P5:A/110-111).*

This question was posed to all the participants and the researcher noted that none of the participants had a desire or need to change anything in their lives. They all seemed quite accepting and content with their lives and experiences thus far.

The following question was also posed to all the participants: "Do you think having a brother or sister with a disability is different from not having a brother or sister with a disability?" The participants revealed quite different viewpoints regarding this aspect. One participant felt that it was a good thing:

*R: Do you think having a brother with a disability is different from not having a brother with a disability?*

*P 4: Well. I do think so. Because in the end it teaches you that you can look after your children when you are older, more better. And also probably you can help them a lot and then you don't fight a lot. Because usually children without that disability does fight a lot (T/P4:A/44-45).*

One participant felt that it would not be different and another revealed that it was quite fun:

*R: Dink jy dit is anders om 'n sussie te hê met 'n gestremdheid as om nie een te hê nie.*

*P2: Dis eintlik lekker om haar te hê.*

*R: Is dit lekker? (with interest in voice)*

*P2: Ja, sy speel lekker BAIE met my (emphasis on the word 'BAIE') (T/P2:A/105-108).*

In addition, one participant with two brothers revealed the following:

*R: Do you think having a brother with a disability is different than having a brother without a disability?*

*P5: They are both different.*

*R: In what way?*

*P5: XXXX (Name) sometimes dresses himself and XXXX (Name) also sleeps in my mom's bed at night. Then the other brother dresses himself and he does not sleep in my mom's bed (T/P5:A/050-053).*

Thus, differences in behaviour were noted, but it did not seem problematic or viewed as an item of concern to the participants.

c) *Sibling relationships*

The findings within the interviews revealed that understandable and quite normal (revealed through literature study) sibling rivalry was experienced within each family. The findings exposed some sibling rivalry between the participants and their brothers or sisters with disabilities. It should be noted that most of the participants revealed that they themselves experienced some form of bullying related to conflict on the part of the brother or sister with disabilities. This could, however, be attributed to the different kinds of disabilities the participants were exposed to. The findings also depicted sibling rivalry between the participants and their other non-disabled siblings. The following extracts contribute and may provide some insight regarding the identified theme:

*P2: Dis eintlik lekker om haar te hê.*

*R: Is dit lekker? (with interest in voice)*

*P2: Ja, sy speel lekker BAIE met my. (emphasis on the word 'BAIE').*

*R: Wat speel julle saam? Wat is julle gunsteling speletjies?*

*P2: Bal vang en skoene gooi vir mekaar. (T/P2:A/106-110).*

*P3: He sometimes swears at us, he calls us names; he is always sometimes mean to us. He tries to hurt us and then we tell our mother and then he says he did not do it. YYYY (the other brother's name is mentioned) is like the same, he is a little bit rude. He sometimes is a little bit of mean. He sometimes hurts me. He does not like playing with me. (The participant has 2 siblings, one with a disability).(T/P3:A/028).*

*R: If you had 3 wishes, what would it be?*

*P3: That if my brothers ever had time to play with me. I will love that. My second wish will be if YYYY and XXXX will stop to be mean. My last wish will be that my brothers will love me more than they dislike me now.(T/P3:A/050-051).*

*P5: He likes to play games with me, especially teacher- teacher. He also likes to play hockey with my other brother. He also likes to play Wii (interactive computer game)*

*R: Do you play with him on the Wii?*

*P5: Yes.(T/P5:A/023-025).*

It should be mentioned that one of the participants brought a photo book to the follow-up interview and this participant enthusiastically and proudly shared the photo book and its contents with the researcher. The photo book contained personal photos of the siblings as they grew up and it displayed a high-quality sibling relationship between the two siblings. There were family photos as well and it seemed as if the family as a unit works well together, although they experience their own challenges.

*d) Personal space and boundaries*

Most of the participants mentioned that there was some form of infringement on their personal space within the home environment on the part of the brothers or sisters with disabilities. The participants revealed that the breaches of personal space or boundaries include verbal, physical or spatial encroachment as is reported in these extracts:

*R: Tell me about the not so good things?*

*P5: When he hurts me. That is all.*

*R: Ok. Tell me about the hurting.*

*P5: He sometimes smacks me (T/P5:A/026-029).*

*P4: Well, (some silence). He does call some people names, but he doesn't do it a lot. He can also be annoying.*

*R: Annoying, tell me a little bit about that.*

*P4: Like sometimes he will take pictures of us and put it on his Ipod. Also like when I'm showering or something, he will just come in and take my clothes and run. It is really fun, (small giggle) but sometimes it is annoying (T/P4:A/013-021).*

*P2: Want sy steel so baie geld. Sy het een keer R500.00 gesteel.*

*R: Ja, waar?*

*P2: My pa se wallet. (a more serious expression on face)*

*R: Weet jy wat het sy met die geld gemaak?*

*P2: Uhm, nee. Al wat sy doen met die yster geld, is dit steel. En sy dink sy kan alles kry (T/P2:A/036-042).*

*P5: If am watching a channel on TV and he wants to go to another channel and I change, then he will start hurting me.*

*R: Ok and then what do you do?*

*P5: I just call my mommy and she comes or my daddy. I have another brother and he says that I must try to ignore XXXX. My mommy also says that I must ignore XXXX (T/P5:A/031-033).*

These experiences may lead to feelings of helplessness due to unequal treatment or unfairness within the family dynamics as siblings might feel that they are wrongly treated. However, it should be noted that most of the participants expressed that they would not change anything in their lives. All the participants expressed their love and care for their brothers and sisters during the interview.

#### **4.2.2.2 Acceptance of child with disabilities as a person**

The findings revealed that the participants did not seem to place too much emphasis on the specific disability their brother or sister experiences, although they were well aware of the purpose of the research. However, all the participants considered some behaviours displayed by their brothers or sisters with disabilities that was either meaningful or matters of concern to them.

The identified themes within this category will be discussed in further detail:

##### *a) Peer perceptions*

Some of the participants revealed that their friends did not know of their brother/sister's disability and on the other hand, some reflected that their friends knew about their brother/sister with disabilities. However, conflicting remarks were made regarding the perceptions of the peers or friends of the participants as some voiced positive perceptions and some voiced negative perceptions as is seen in the following extracts:

*R: Do your friends know that your brother has a disability?*

*P4: Yes. And they understand. They actually kind of like my brother (T/P4:A/078-079).*

*R: By jou skool, weet die kinders van jou sussie se gestremdheid?*

*P2: Nee.*

*R: Sal jy hulle eendag kan sê?*

*P2: Nooit, want hulle gaan vir my lag. Hulle gaan dink dit is nie waar nie (T/P2:A/143-146).*

*P2: Hulle sê sy is eintlik stupid. Hulle dink nie sy is nie gestrem nie. Hulle dink sy is stupid. Hulle weet nie wat gestrem is nie.*

*R: Voel jy jy kan hulle vertel daaroor?*

*P2: Ek voel ek kan, maar ek wil nie. Want dit voel nie lekker nie. Hulle sal vir my lag, want hulle weet nie wat gestrem is nie (T/P2:A/162-164).*

*R: Does having XXXX as a brother limit what you can do at home, at school or with your friends?*

*P3: No. (silence). Sometimes with my friends, he will act like he is in love with my friends and then he will start calling us names. My friend doesn't like coming over to my house anymore and now I go to her house (T/P3:A/080-081).*

*R: And what did she (friend's name) say?*

*P3: She says that she also doesn't really like XXX (the participant's brother/sister). It makes me feel a bit unhappy because my brothers are very special to me (T/P3:A/101-103).*



*b) Awareness of disability*

The participants remarked that they were all aware of the disabilities their brothers or sisters experience. None of the participants could provide specifics regarding the disabilities. However, they could provide some detail concerning their brothers' or sisters' behaviour.

*R: Ok, what is it like to have XXXX as a sister?*

*P1: She likes playing a lot. She does get angry sometimes, she also hits a lot. We got a puppy ... and she enjoys playing with CCCC (the dog). She loves to be sporty and after one of her operations this year she wasn't able to run at all and we are looking for a school for her for next year. Because the school that she is in now has kicked her out for next year. Because she does not have any emotional sign of feelings (T/P1:A/020-021).*

*R: Ok, kan jy vir my sê wat is 'n gestremdheid?*

*P2: Ja, dis 'n bietjie soos dom wees (T/P2:A/005-006).*

*P1: The hitting; the punching; the kicking; the swearing; the screaming; the shouting...*

*R: And how does that make you feel?*

*P1: It sort of makes me feel depressed and hurt, especially in front of my friends, it makes me feel embarrassed. But that is the way she is going to be...(T/P1:A/031-033).*

*P4: I usually on the weekends wash my dad's car. And to keep my brother busy I blow the leaves that fall, but now we have to put some compost down on the grass. We still haven't finished that yet. But my brother loves doing those kinds of things so I keep him busy doing it. But we don't get money and I don't mind (T/P4:A/057).*

*c) Wellbeing wishes / Concerns*

Most of the participants remarked that they had some concerns regarding their brother's or sister's wellbeing. In addition, some also replied, when asked about their wishes, that they wished for their brother or sister to be well, as represented in the following extracts:

*R: If you had any 3 wishes what would it be?*

*P1: I wished that my sister was not brain damaged and I wish my friends would not be mean to me, sometimes. And my friends would not make fun of me.*

*R: What about the first wish about the brain damage. Can we talk about that?*

*P1: That she was able to walk better, to talk better, because her talking is not any good (T/P1:A/042-045).*

*R: Do you worry about your brother with disabilities?*

*P5: Ummm (thinking) Sometimes.*

*R: What do you worry about?*

*P5: We were reading a book last night and he struggles with some words.*

*R: Ok and why do you worry about that?*

*P5: Because I get all of the words right and he does not get all the words.*

*R: And how does that make you feel?*

*P 5: Sad (T/P5:A/054-061).*

*R: Ok. If you had any 3 wishes, what would they be?*

*P4: My first one would be to cure my brother's problem....(T/P4:A/032-033).*

*R: Ok. So your first wish was to cure your brother's problem. Tell me a little bit about that wish.*

*(Some silence). What would you want to do and what would you like to do?*

*P 4: He would probably be able to read more, so we can teach him from grade one all the way through again, so that he can understand better. And then he can get a proper job (T/P4:A/034-035).*

#### **4.2.2.3 Adult / Parental factors**

The participants live in their respective homes and are faced with their own unique challenges and this means that important adults in their lives would be part of their inner system. Thus, the identified themes within this category will be discussed in further detail:

##### *a) Divulgence of needed information*

Some questions revolved around adults revealing information regarding the disability and most of the participants voiced that their parents did discuss some information regarding the disabilities experienced by their brothers or sisters as evident in the following extracts:

*R: Has someone like your mom or dad or someone else talked to you about her disability?*

*P1: My mother has a bit, but not too much in detail.*

*R: Ok. And what did she say?*

*P1: She said that she (meaning sister) was in and out the hospital quite a lot and the doctors put a needle in her when she almost did not have veins when she was young what caused her to swell up and umm that is all (T/P1:A/034-037).*

*P3: (nods head affirmatively – yes). XXXX was born yellow and he had a disability. The doctors in the hospital said he would not be able to walk or talk so we were just afraid about that. He was the first born so. And then he actually did a lot of those things. He is doing very well in walking and*

*very well in talking. When he was four or five or two, he started to talk. So they were quite surprised (T/P3:A/039).*

*R: Has anyone like your mother or father talked to you about XXXX's disability?*

*P4: Ja, they have spoken to me about it, but not much. Once when he went for a test, I think, and it said that he can't improve the way he is now. We were sad but we understand it now, we can help him still. We try.*

*R: Ok and what did your mom and dad say? How did they explain it to you?*

*P4: I can't remember what it is called, but they said that he has a problem with remembering things. They said that he can't read and write, but he can write some words, but he can't pronounce words right. He will read out the letters like "T- H- E" (says letters slow and phonetically).*

*R: And do you help him?*

*P4: Yes I help him (T/P4:A/024-029).*

#### *b) Time management and togetherness*

The participants were asked whether they felt that they spent enough time with their parents. Most of the participants revealed that they did spend adequate time with their parents. However, from the extracts it can be affirmed that they also mentioned that they would like to spend more time with their parents:

*R: Ok. Do you have special time alone with mom and dad?*

*P1: Umm, probably 5 minutes every single day.*

*R: Ok, would you like more time?*

*P1: Yes.*

*R: And what would you like to do with mom?*

*P1: I would like to go shopping with her even if I don't like it that much. (laughs a bit while saying this), justto make her happy and that my dad can stop going away so much that I can spend time with him (T/P1:A/060-065).*

*R: Do you have special alone time with mom and dad?*

*P3: Sometimes. When YYYY goes to a friend and XXXX goes to the farm, I have time with my mom and dad.*

*R: What do you like to do when you have alone time with mom and dad?*

*P3: All I do is watch a nice movie with my mom and dad or if they are too busy, I will ask them to read with me (T/P3:A/072-075).*

*R: Do you have special alone time with your mom and dad?*

*P 4: No. Mostly my sister is with my mom and dad. And sometimes she is with my gran. And so then my mom and I get lots of time together. We like going to the shops together and my sister doesn't really like shopping, but I love going shopping with my mom. I don't get so much time with my dad (T/P4:A/060-061).*

#### **4.2.2.4 Adequate information and support regarding the brother / sister's disability in society and at home**

The participants revealed that they all had some information about the disabilities their brothers or sisters were experiencing. One participant revealed that he or she discussed the disability his or her brother or sister experiences with a professional person (i.e. psychologist). In addition, other participants did not disclose that they either discussed or had a desire to discuss the disability with someone else. The identified themes within this category will be discussed in further detail:

##### *a) Family involvement*

One participant revealed the following: *P3: Yes, my ouma sometimes says when I want to say ugly things to him (meaning brother), I must just ignore it and then I just say nice things (T/P3:A/035).* In addition, another participant expressed the following: *P2: Ja, sy kan baie by ouma en oupa wees (T/P2:A/059).* However, most of the other participants did not reveal anything specific about other family members' involvement regarding their brother or sister with disabilities. It seems as if the grandparents play a supportive role in some of the families' lives.

##### *b) Being informed*

Some participants revealed that there was a need for more information and one participant disclosed that he or she would prefer not to know more about the disability and one participant revealed that she was not sure, as can be seen from the following extracts:

*R: Would you want to know more about her disability?*

*P1: Yes (T/P1:A/038-039).*

*R: Would you like to know more about XXXX's disability?*

*P3: I am not sure because there is a lot of things about his disability (T/P3:A/044-045).*

*R: Would you like to talk to someone about having a brother with disabilities?*

*P5: (Silence) No (T/P5:A/108-109).*

*R: Have you ever talked to someone about your brother XXXX?*

*P4: No, I don't know... Umm. Maybe, Ja. The psychologist (T/P4:A/100-101).*

### *c) Voice emotions and feelings*

Some of the participants expressed their feelings and emotions throughout the interviews. The researcher felt that this may prove to be an important aspect of these children's lives, as they are exposed to quite different challenges and voicing emotions may be important to them as individuals. The researcher sees this aspect as valuing the unique and individual views, perceptions and experiences of each participant as is depicted in the following extracts:

*R: And how did that make you feel?*

*P4: It made me feel a lot better because he (the psychologist) said it is actually nice to have a disability brother because you can help him a lot and then you will know how to treat your children when you are older and he said he will play more than a non-disability brother would play (T/P4:A/102-103).*

*R: Het jy al met iemand anderste gepraat oor hoe dit voel om 'n sussie te hê met 'n gestremdheid?*

*P 2: Ja. (nods head as well)*

*R: Met wie het jy al gepraat?*

*P2: Met van my maatjies by die skool. Die ander skool.*

*R: En hoe het dit jou laat voel?*

*P2: Bietjie funny. (T/P2:A/173-178).*

*P1: The hitting; the punching; the kicking; the swearing; the screaming; the shouting...*

*R: And how does that make you feel?*

*P1: It sort of makes me feel depressed and hurt, especially in front of my friends, it makes me feel embarrassed. But that is the way she is going to be.... (T/P1:A/031-033).*

*P1: I spoke to my friend ZZZZ*

*R: And how did it make you feel to talk to someone?*

*P1: It made me feel comfortable because I knew he had more or less the same problem with his cousin (T/P1:A/104-106).*

## **4.3 DISCUSSION OF THE FINDINGS**

### **4.3.1 How do siblings of children with disabilities describe and view themselves as individuals?**

The overall findings suggest that the siblings of children with disabilities see themselves as individuals and as part of the group. However, the siblings in this study did not go to the same school as their brothers or sisters with disabilities. Furthermore, according to the participants, they see themselves as children who enjoy to play, therefore, their brothers or sisters with disabilities

may be a good playmate, at present, as they could spend time together playing games. In addition, the participants seem to focus a great deal on school and extra-mural activities, which appears to be quite important to them. This may be related to the fact that they are in their middle childhood phase where the external environment, including school and co-curricular activities are important aspects of their lives. Most of the participants did not reveal any extra responsibilities within the household. However, one participant revealed that he usually keeps the brother with disabilities busy, especially over weekends, thus he sees himself as a caretaker of the brother with disabilities.

#### **4.3.2 What challenges do siblings of children with disabilities encounter in their lives?**

The participants revealed that some of them would prefer not to take friends home or to disclose to their friends at school that they have a brother or sister with disabilities. The participants revealed that they would want to spend more one-on-one time with their parents as they feel that they are not spending enough quality time with them. A challenge that most of these participants expressed was the fact that they experienced some form of intrusion on their personal space, physical, verbal or spatial. These experiences may lead to feelings where the participants perceive there to be unequal treatment of the children. In addition, some of the participants revealed in their three wishes that they wished to help their brothers or sisters with their disabilities so that they could learn more easily. The participants also revealed concerns that they have about their brothers and sisters with disabilities.

#### **4.3.3 Is there a need to support siblings of children with disabilities?**

The participants revealed that they do not really know of friends that also have brothers or sisters with disabilities within their homes; thus, they do not actually seem to have someone to talk to, except maybe their parents or other close family members. The participants revealed contradictory remarks regarding support. However, they all seem to disclose some of their personal lives, including their brother or sister with disabilities, to friends. Thus, the children may need adequate information regarding the disabilities if they would want to disclose it to their peers. In addition, the participants expressed that their parents revealed some information regarding the disabilities their brothers or sisters experience. However, children may need additional information as they grow up, and especially if they spend so much time with their brothers or sisters with disabilities. Furthermore, the aspect of intrusion, mentioned in section 4.3.2 appears to be a relevant discussion point in this section, as it proves to be an infringement on their personal space. This may be due to the fact that the participants seem to have grown accustomed to the person the brother or sister was and as some of them did not notice the disability and the impact it may or may not have on their lives.

#### **4.4 CONCLUSION**

In this chapter the empirical research exploration, including the data analysis procedure and the data analysis interpretation were described and discussed in great detail. Hence, the various identified categories and themes were identified and used to reflect participants' personal views, perceptions and experiences regarding their brother or sister with disabilities and the impact this may or may not have on their own lives. Thereafter, these research results were discussed according to the main research questions raised in an endeavour to gain a rich and in-depth understanding of how the disabilities of a child could impact on a non-disabled sibling.

In Chapter 5 the summaries of the literature study and the empirical study are discussed as well as the limitations of the study and recommendations for further study.

## **CHAPTER 5**

### **FINDINGS, RECOMMENDATIONS AND CONCLUSION**

*“No one has yet fully realised the wealth of sympathy, kindness and generosity hidden in the soul of a child. The effort of every true education should be to unlock that treasure.”*

*Emma Goldman (Famous quotes about children)*

#### **5.1 INTRODUCTION**

This chapter provides an overview of the study with reference to the aim of the research, summary of the literature review and empirical findings. Thereafter, shortcomings are presented and recommendations for further research are made before a final conclusion is provided.

#### **5.2 PURPOSE OF THE RESEARCH**

The primary purpose of this research was to gain a rich and in-depth understanding of how disabilities of a child could impact a non-disabled sibling. Consequently, the following specific research questions were produced:

- How do siblings of children with disabilities describe and view themselves as individuals?
- What challenges do siblings of children with disabilities encounter in their lives?
- Is there a need to support siblings of children with disabilities?

In order to achieve the research aims, the researcher has made use of a qualitative research method. Since, according to Willig (2012:6), qualitative research endeavours to enhance the understanding of how people make sense of their experiences and what people's actions mean, both to themselves and to others. Furthermore, according to Shaughnessy, Zechmeister and Zechmeister (2012:43), qualitative research produces verbal summaries of research findings. Thus, this study intended to gain valuable insight into the lives of siblings of children with disabilities. The target population of the study included information rich participants who are siblings to children with disabilities. Therefore, participants were purposively selected. In addition, the target population was further delimited by exclusively including participants who were in their middle childhood phase. This means inclusion of children who are between the ages of six and twelve years and exclusion of children outside the mentioned age perimeters.



## **5.3 SUMMARY OF LITERATURE AND EMPIRICAL INVESTIGATION**

### **5.3.1 Literature summary**

The literature review established that children from part of a larger social scheme wherein they influence, and are influenced by various environments (Gargiulo & Kilgo 2010:54). In this context interrelationships and interactions of individuals within the environment are found (Gargiulo & Kilgo 2010:54). Furthermore, families face many challenges throughout their lives that will have an impact on the entire family (Negron 2007:5). Therefore, Bronfenbrenner's ecological systems perspective could be used as a perspective to understand the relationship between the immediate environments in which a child develops and the larger contexts of those settings (Gargiulo & Kilgo 2010:54). Therefore, according to Gargiulo and Kilgo (2010:54), a developing child cannot be viewed in isolation but rather as part of a larger social system. Thus, there should be appreciation for the child's total environment—home, school, community, and the larger society, in addition to the individuals encountered therein—parents, siblings, classmates, playmates, and therapists among other people (Gargiulo & Kilgo 2010:54). Although specific research questions were examined in the literature review, they are completely intertwined as they contribute to the whole experience of the sibling; including their personal views of themselves, the challenges the siblings are facing and identifying the need to support these siblings. Therefore, an understanding of the impact of disability on siblings of children with disabilities must be accompanied by an analysis of the relationship between the siblings and their brothers or sisters with disabilities, in order to address the challenges the siblings are faced with as well as to identify whether there is a need to support these siblings.

The sibling sub-system may be quite significant as siblings spend a considerable amount of time with each other. Within these interactions the siblings learn social skills from each other, including sharing and identifying responsibilities, competition and working together. Thus, the sibling relationship may be one of the most enduring and influential bonds a person may encounter. In addition, during middle childhood children spend most of their day at school and with their friends and peers. Opportunities for social interaction increases and becomes more increasingly important. Thus, children's sense of belonging expands and incorporates peers and social inclusion during middle childhood.

Inclusion resulted in a movement from the medical model to a social model of disability. The medical model views disability as something that must, whenever possible, be cured (Tassoni, Beith & Bulman 2005:315). Furthermore, the medical model of disability tends to put the emphasis more on the condition rather than on the person (Tassoni *et al* 2005:315). On the other hand, the social model empowers people as it emphasises their rights to make choices and be independent (Tassoni, Beith & Bulman 2005:315). Therefore, within a social model of disability, the children with disabilities are viewed as children "with a capacity for development, however limited it may be"

(Broster 2006:32). Consequently, the literature review explored a variety of needs, demands and expectations of children with disabilities on various levels including adaptations made by family members, appropriate care and support needs. However, the siblings of children of disabilities are also active, contributing participants within their sibling bond and family as well as within the wider community and society where they adapt and develop accordingly. Thus, the siblings of children with disabilities have their own unique needs and expectations as children; as developing contributors within society and as members of a family.

With the above mentioned taken into account, siblings of children with disabilities are faced with an array of unique challenges that may change as the siblings develop. The literature review exposed and recognised variances regarding sibling experiences about living with children with disabilities. Positive experiences and facets of living with children with disabilities were identified, which include, but are not limited to, earlier maturation due to increased responsibilities, greater empathy and tolerance for people with disabilities, being more helpful, caring and understanding. In contrast, complex experiences and facets of living with children with disabilities were revealed. These include, but are not limited to, concerns regarding the sibling's disability, jealousy due to increase attention, fear, anger, pressure to perform and to be the perfect child, guilt, resentment as well as embarrassment and increased responsibilities. Consequently, the siblings of children with disabilities have a vast amount of needs and expectations quite different from the children with disabilities. Hence, the identification of the call towards providing support to siblings of children with disabilities was essential.

The family has been recognized as an important role player in supporting siblings of children with disabilities. In addition, the family has been acknowledged as an important role player, in general, regarding families with children with disabilities. These family members could provide emotional support to any member as needed. They could also provide practical resources and information to the family members about the challenges, possibilities and disabilities they are confronted with. Furthermore, the literature findings suggest that there appears to be a great necessity to support siblings of children with disabilities, seeing as their own individual views, experiences and needs are not always noticed or taken into account. Identified areas of support include the following, among others: sharing experiences, providing correct and age appropriate information about the disabilities and relevant information about raised concerns, sensitive parenting and providing opportunities for self-expression. However, the siblings need regular, understandable and updated information as they grow up, regarding the challenges the families are faced with, pertaining to the disabilities experienced, within this nested system. Thus siblings of children with disabilities should be acknowledged as active contributors to the family system.

In conclusion, the following quote from Nelson Mandela, the former president of South Africa, as recorded from 'Famous quotes about children: Compassion International': "There can be no keener revelation of a society's soul than the way in which it treats its children."

### **5.3.2 Summary of the empirical investigation**

Siblings of children with disabilities, who found themselves in their middle childhood phase, were identified as the contributors to the empirical investigation that was discussed and explored in Chapter 4. Thus, relationships were explored within the family subsystem, the sibling subsystem and within the community and the wider society to discover the impact of disability on siblings of children with disabilities.

The participants identified themselves as unique individuals with dreams and goals to reach within their individual lives. They revealed that they are active members of community, within the wider society and within their school and home environment as they actively participate in extra-mural activities and they get pleasure from their schooldays. The participants identified friends and peers as important role players in their lives.

The following significant challenges were identified by the participants who are the siblings of children with disabilities: experiences of intrusion in personal space and time, a level of conflict on part of the children of disabilities (i.e. impulsive behaviour and struggling to stick to personal boundaries), limited parental time and attention, concerns about taking friends home as well as concerns about revealing information about the disabilities experienced within the family to their friends and peers. Some of the siblings acknowledged an increased sense of responsibility towards their brothers or sisters with disabilities. The siblings voiced their emotions concerning behaviours that were displayed by the children with disabilities. These aired emotions included: sadness, embarrassment, anger and being upset as well as care, love, empathy and admiration. However, on the other hand, the siblings revealed that the children with disabilities were considered as quite good friends of theirs, considering that they could play together since the children with disabilities were willing to play with them. In addition, the findings revealed that, although the siblings and their families are challenged with difficulties, they prefer not to change anything in their lives. Thus, the siblings did not seem to focus on the disability, they rather expressed behaviour traits that stood out, which they experienced as dominant problem areas.

The findings of this empirical investigation revealed that not all the siblings identified the same experiences as shared experiences of being siblings to children with disabilities. This means that even though similarities between specific answers and revelations were identified, the overall experiences were not the same. Thus, unique variables of experiences were identified, regardless of exploration of repeated experiences. This means that internal factors such as character traits,

resilience and personality development could be taken into account as important factors in the relationship dynamics between the siblings and the children with disabilities. The findings of this empirical investigation identified that, in fact, there does seem to be a great need to support siblings of children with disabilities. The challenges they are faced with should be taken into account and they revealed that there seems to be a need to support these siblings and their families, since a child does not live in isolation and since the whole family is a nested system interacting with each other, within the family system and with other systems beyond the family system, including the wider community and society.

#### **5.4 LIMITATIONS OF THIS STUDY**

- The fastidious over reliance on too many sources, stifled my creativity to construct data based on the rich narratives of the siblings.
- Parents of the siblings of children with disabilities could have been included as research participants to corroborate the siblings' claims and contexts.
- Generalisations about siblings of children with disabilities cannot be made from this study as it is a qualitative research study wherein an in-depth understanding, pertaining to the views and experiences of participating children, was the focus. Furthermore, generalisations cannot be made about the siblings of children with disabilities, as this experience, of living with a brother or sister with disabilities is purely a facet of their lives. This means that there could be a variety of influences impacting upon their lives, including internal and external factors, which results in unique experiences by the siblings of children with disabilities.
- This study did not focus on a specific disability, thus different views of disabilities should have been taken into account as well as individual differences or experiences regarding the exposure to the same disabilities.

#### **5.5 RECOMMENDATIONS FOR FURTHER STUDY**

The study focused on understanding the views and experiences of siblings of children with disabilities. The following recommendations can be made for further study towards a more comprehensive understanding regarding disabilities experienced within families in the South African context.

- Parental views, the views of the children with disabilities, peer group views, and even views within the community may provide insight into all the aspects that may have an impact on the siblings of children with disabilities.

- Specific attention was given to siblings that were in their middle childhood phase. This means that other age group views and experiences were not taken into account. Hence, this may be required for further research relevant to each age group, as each age group's views and experiences may focus on different aspects of sharing a sibling bond and environment with children with disabilities.
- South Africa has only fairly recently acknowledged and promoted the paradigm shift from the medical model of disability to the social model of disability. Therefore, recognition of inclusive settings, including the home environment, the school environment, the community and wider society prove to be areas of further research within the South African context.
- Design, implementation and constant monitoring of the effectiveness of support programmes introduced in the South African context is needed to establish the particular challenges, in order to provide valuable explanations of these challenges experienced within the South Africa context.

## 5.6 CONCLUSION

This study aimed to understand how the disability of a child could impact on a sibling. This in-depth understanding has been realised by means of a comprehensive literature review and the exploration of the siblings' views and experiences through the interpretation of data collected using interviews, documents and observations. The study illustrated that siblings of children with disabilities embrace their sibling bonds, even though the siblings are exposed to and challenged with disabilities. Thus, inclusivity, within the family system and within society as a whole, is confirmed and recognised. However, the study confirmed that siblings of children with disabilities experience unique challenges and this validates the necessity to provide support to these children and their families as they are valued and recognised as contributing members within their families, within their peer groups, as well active contributors as citizens, within their wider community, resulting in empowering others and improving life within the wider society as strikingly illustrated hereunder..

### **Michael – My younger brother**

**M** – is for Michael – my younger brother who was born with Global Developmental Delay.

**I** – If only everyone realised that he isn't that different from them.

**C** – Contagious – Michael's smile is contagious.

**H** – Hope is what I have in God for Michael.

**A** – Able to touch our hearts with his zest for life.

**E** – Easy going and care free.

**L** – Love is the gift he brings to our family.

*Young carer 10 years (Young carer poems)*

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## **ADDENDA**

### **Addendum A: Letter to the Headmaster requesting permission to undertake research at the institution.**

19 June 2012

---

To whom it may concern

#### **REQUEST FOR CONSENT**

I, Celeste Janse van Vuuren, an enrolled student at the University of South Africa, herewith kindly request consent to conduct a research study at and in association with your school.

I am currently enrolled in the Master's Degree of Education Programme with specialisation in Guidance and Counselling. I am in the process of writing a dissertation under the supervision of Professor Deirdré Krüger. As a requirement of my studies, I am engaged in an empirical research study entitled "The impact of disability on siblings of children with disabilities". This study aims to gain an in-depth understanding of how the disabilities of a child could impact a non-disabled sibling.

In addition, the study focuses on non-disabled children between the ages of 6 and 12, that have siblings with disabilities. In light of the aforesaid I would like to determine whether there are families within your school who fall within this category.

In the event that you permit me to do so, I would address written requests to the relevant families, for the parents and / or guardians' permission to allow their children to participate in the intended study.

The questions I endeavour to answer are the following:

- How do siblings of children with disabilities describe and view themselves as individuals?
- What challenges do siblings of children with disabilities encounter in their lives?
- Is there a need to support siblings of children with disabilities?

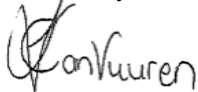
Any and all personal and private information, which may be regarded as sensitive, including but not limited to names and locations will be treated with utmost confidentiality and anonymity throughout and subsequent to the study.

In order to enable me to proceed with the necessary steps, kindly furnish me with your written consent on a school letterhead.

Your permission, as requested herein, would be greatly appreciated. Should you have any questions and / or concerns in this regard, please do not hesitate to contact me.

Thanking you in advance for your kind assistance.

Yours faithfully,



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Celeste Janse van Vuuren

Researcher (Unisa student number: 35038837)

Email: [celeste@childkinetics.com](mailto:celeste@childkinetics.com)

Tel: 0829215236

**Addendum B: Letter from the Headmaster providing permission to undertake the research at the institution.**

20 JUNE 2012

Dear Ms. C. Janse van Vuuren

The purpose of this letter is to grant you, Celeste Janse van Vuuren, a student at the University of South Africa, permission to conduct your proposed empirical research project entitled “The impact of disability on siblings of children with disabilities” at \_\_\_\_\_ towards your Master’s Degree.

We are aware that this project involves recruiting students of this institution to participate in your research project. We understand that all information collected from individuals will be done with duly informed consent from the participating individuals and their parents or guardians and that these individuals can refuse participation with no negative consequences for said individual.

We support the conduct of this research project in this institution and we would be grateful were you to share the results with us.

Kind regards

\_\_\_\_\_

\_\_\_\_\_

**HEADMASTER**

## **Addendum C: Letter of Consent: Request for consent (English).**

### **REQUEST FOR LETTER OF CONSENT**

**Research Study by Celeste Janse van Vuuren:** “The impact of disability on siblings of children with disabilities”

Date

Dear Parent / Guardian

I, Celeste Janse van Vuuren, an enrolled student at the University of South Africa, herewith kindly invite you and your family to become involved in my research study.

I am currently enrolled in the Master’s Degree of Education Programme with specialisation in Guidance and Counselling. I am in the process of writing a dissertation under the supervision of Professor Deirdré Krüger. As a requirement of my studies, I am engaged in an empirical research study entitled “The impact of disability on siblings of children with disabilities”. This study aims to gain an in-depth understanding of how the disabilities of a child could impact a non-disabled sibling.

In addition, the study focuses on non-disabled children between the ages of 6 and 12, that have siblings with disabilities. In light of the aforesaid I am requesting your consent to allow your son or daughter to participate in this study. Approximately 6 (SIX) children, who have siblings with disabilities, will be asked to anonymously participate in this study. If your child participates, he or she will be interviewed, at school or your home, at a time that suits your schedule during the month of August 2012. The interview will last no more than 30 minutes. The interview will be recorded on audiotape for research purposes only. In addition to the interview, your child will be asked if he or she would be interested in sharing any other collateral information, for instance his or her highlights, in the form of a “My own highlights” sheet as documentation. Such documentation may provide valuable information in this study. This documentation as collateral information will be treated with respect and confidentiality. A follow-up interview may be scheduled to discuss the relevant documentation if necessary.

I do not anticipate any risks associated with this process, should your child participate in this study.

I endeavour to answer the following research questions throughout the interview:

How do siblings of children with disabilities describe and view themselves as individuals?

What challenges do siblings of children with disabilities encounter in their lives?

Is there a need to support siblings of children with disabilities?

Your child's participation in this research study is completely voluntary. In addition to your consent, your child will also be asked if he or she would like to take part in this study. You are free to withdraw your consent for your child's participation at any time and for any reason without penalty. There are no costs involved and no compensation will be given to participating families in this research study.

Any and all personal and private information, which may be regarded as sensitive, including but not limited to names and locations will be treated with utmost confidentiality and anonymity throughout and subsequent to the study. Any findings pertaining to this research study will be made available for your perusal should you wish to examine them.

Your consent, as requested herein, would be greatly appreciated. Should you have any questions and / or concerns in this regard, please do not hesitate to contact me. Should you be willing to be of assistance by providing the requested consent, kindly complete and sign the attached Consent Form and return to writer hereof at your earliest convenience.

Thanking you in advance for your kind assistance.

Please also find attached hereto a copy of this letter and Consent Form for your recordkeeping purposes.

Yours faithfully,

---

Celeste Janse van Vuuren

Researcher (Unisa student number: 35038837)

Email: celeste@childkinetics.com

Tel: 0829215236

**Consent Form – Research Study by Celeste Janse van Vuuren: “The impact of disability on siblings of children with disabilities”**

I, \_\_\_\_\_, (name and surname of parent/guardian) the parent / guardian of \_\_\_\_\_ (name and surname of child), hereby grant consent for my child to participate in the above mentioned research study. I am aware that no risk is anticipated in relation to participation of my above mentioned child in this study and that I am entitled to withdraw this consent at any time without penalty or consequence.

I am further aware and accept that no remuneration will be provided to any family, parent, child or otherwise in return for such participation.

I confirm that my above mentioned child's participation is completely voluntary and my child's consent shall be requested prior to my proceeding to sign this document.

I understand that I am under no legal obligation to provide this consent and same is herewith given on a voluntary basis. By providing this consent and by appending my signature to this document, I irrevocably confirm and state that I am indeed the parent and/or guardian of the above mentioned child and therefore I am duly authorised of providing such consent to the researcher.

Signed at \_\_\_\_\_ on this the \_\_\_\_\_ day of \_\_\_\_\_ 2012.

\_\_\_\_\_  
Signature: Parent/Guardian

\_\_\_\_\_  
Date

## **Addendum D: Letter of Consent: Request for consent (Afrikaans).**

### **VERSOEK OM TOESTEMMING**

**Navorsingstudie deur Celeste Janse van Vuuren:** "Die impak van gestremdheid op die broers en susters van kinders met gestremdhede"

Datum

Geagte Ouer/Voog

Ek, Celeste Janse van Vuuren, 'n ingeskrewe student aan die Universiteit van Suid-Afrika, nooi hiermee u en u gesin om betrokke te raak met my navorsingstudie.

Ek is tans ingeskryf as 'n Meesterstudent in Opvoedkunde met spesialisering in Voorligting. Ek is in die proses van die skryf van 'n verhandeling onder die toesig van Professor Deirdré Krüger. As 'n vereiste van my studies, is ek betrokke by 'n empiriese navorsingstudie, getiteld "Die impak van gestremdheid op die broers en susters van kinders met gestremdhede". Hierdie studie het ten doel om 'n in-diepte begrip te verkry van die impak wat kinders met gestremdhede op 'n nie-gestremde broer of suster mag hê.

Daarbenewens fokus die studie op nie-gestremde kinders tussen die ouderdomme van 6 en 12, wat broers en susters met gestremdhede het. In die lig van die voorafgaande vra ek u toestemming om u seun of dogter se deelname aan hierdie navorsingstudie. Ongeveer 6 kinders, wat broers en susters met gestremdhede het, sal gevra word om anoniem deel te neem aan hierdie navorsingstudie. Indien u kind sou deelneem, vereis die navorsingstudie dat 'n onderhoud, tydens die maand van Augustus 2012, met u kind, by u huis, of by die skool, gevoer word. Die onderhoud behoort nie langer as 30 minute te duur nie. Die onderhoud word opgeneem op oudioband vir navorsingsdoeleindes. Bykomend tot die onderhoud, mag u kind gevra word, indien hy of sy geïnteresseerd sou wees, om bykomende inligting, soos u kind se hoogtepunte, in die vorm van 'n "My eie hoogtepunte" bladsy, as dokumentasie te deel. Sodanige dokumentasie mag waardevolle inligting in hierdie navorsingstudie verskaf. Hierdie dokumentasie sal met uiterse vertroulikheid hanteer word. 'n Opvolg-onderhoud mag gereël word om die dokumentasie te bespreek en /of indien dit nodig geag sou word.

Ek verwag geen risiko met die bogenoemde proses indien u kind sou deelneem aan hierdie navorsingstudie.

Ek gaan poog om die volgende vrae tydens onderhoud te beantwoord:

- Hoe beskryf en sien broers en susters van kinders met gestremdhede hulself as individue?
- Watter uitdagings ondervind broers en susters van kinders met gestremdhede in hulle daaglikse lewens?
- Is daar 'n behoefte om broers en susters van kinders met gestremdhede te ondersteun?

U kind se deelname aan hierdie navorsingstudie is heeltemal vrywillig. In toevoeging tot u toestemming, sal u kind ook gevra word indien hy of sy wil deelneem. Dit staan u verder vry om ter enige tyd of ter enige rede, sonder straf, u toestemming te onttrek. Daar is geen kostes aan verbonde nie en geen vergoeding sal gegee word aan die deelnemende gesinne in hierdie navorsingstudie nie.

Enige en alle persoonlike en privaat inligting, wat as sensitief beskou word, insluitend maar nie beperk tot name en plekke, sal met die uiterste vertroulikheid en anonimiteit gedurende en na afloop van die navorsingstudie behandel word. Enige bevindinge met betrekking tot hierdie navorsingstudie sal beskikbaar gestel word vir u insae indien u dit sou wou ondersoek.

U toestemming, soos versoek hierin, sal opreg waardeur word. Indien u enige vrae en / of kommentaar in hierdie verband het, moet asseblief nie huiwer om my te kontak nie. Indien u bereid is om van hulp te wees deur die verskaffing van die verlangde toestemming, voltooi asseblief die aangehegte toestemmingsvorm en besorg terug aan die skrywer hiervan.

Byvoorraat dank.

Vind asseblief ook hierby aangeheg 'n afskrif van hierdie skrywe en toestemmingsvorm vir u rekordhouding.

Die uwe,

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Celeste Janse van Vuuren  
Navorser (Unisa studentenommer: 35038837)  
E-pos: [celeste@childkinetics.com](mailto:celeste@childkinetics.com)  
Tel: 0829215236



**Ooreenkoms / Toestemmingsvorm – Navorsingstudie deur Celeste Janse van Vuuren: "Die impak van gestremdheid op die broers en susters van kinders met gestremdhede"**

Ek, \_\_\_\_\_, (naam en van van ouer / voog) die ouer / voog van \_\_\_\_\_ (naam en van van u kind), verleen hiermee toestemming vir my kind om deel te neem in die bogenoemde navorsingstudie. Ek is bewus daarvan dat daar geen gevaar en/of risiko bestaan met betrekking tot my bogenoemde kind se deelname aan hierdie navorsingstudie nie en dat ek geregtig is om hierdie toestemming enige tyd te onttrek, sonder straf of nagevolge.

Ek is verder daarvan bewus en aanvaar dat geen vergoeding voorsien sal word aan 'n familielid, ouer, kind of ander persoon in ruil vir sodanige deelname nie.

Ek bevestig dat my bogenoemde kind se deelname heeltemal vrywillig is en dat my kind se toestemming versoek sal word voor die aanvang van die navorsingstudie.

Ek verstaan dat ek onder geen wetlike verpligting is om hierdie toestemming te verskaf nie en sodanige toestemming word hiermee verleen op 'n vrywillige basis. Deur die verskaffing van hierdie toestemming en deur die aanbring van my handtekening tot hierdie dokument, bevestig en verklaar ek dat ek die ouer en / of voog van die bogenoemde kind is en daarom behoorlik gemagtig is om hierdie toestemming te verleen aan die navorser.

Geteken te \_\_\_\_\_ op hierdie \_\_\_\_\_ dag van \_\_\_\_\_ 2012.

\_\_\_\_\_  
Ouer / Voog

\_\_\_\_\_  
Datum

## **Addendum E: Letter of Assent: Informed Assent (English).**

### **LETTER OF ASSENT**

Date \_\_\_\_\_

Dear \_\_\_\_\_

My name is Celeste Janse van Vuuren. I am a student at the University of South Africa. I am doing a research study entitled "The impact of disability on siblings of children with disabilities". This study hopes to understand how the disabilities of a child (your brother or sister) could impact a non-disabled sibling (you). A research study is a way to learn more about people. Being part of this study will allow you to share your information that could be used to better understand this topic.

If you decide that you want to be part of this study, you will be asked to have an interview (chat) with me at your home or at school and at a time that suits your schedule. The interview will be no longer than 30 minutes. The interview will be recorded on audiotape for my research. I need the recording to study the information after we had our chat.

You will also be asked if you would like to share your own highlights or any other extra information. There is a "My own highlights" page that you can fill in. This information in the form of documentation may assist me in my research study. I will respect the information shared and it will remain confidential. A follow-up interview could be arranged to talk about this information or if there is anything else that you would like to share about this topic.

You do not have to be in this study if you do not want to. If you decide to stop after we begin, that's okay too. No one will be mad at you if you decide not to do this study. You may ask questions about the study at any time. I do not foresee any risk if you decide to participate in this study. If you feel uncomfortable about any question at any time, you do not have to answer the question. When I am finished with this study, I will write a report about what was learned. This report will not include your name or state that you were in this study. You will not receive any gifts or money for agreeing to be part of this study.

Please discuss this with your parents before you decide whether or not to be part of this study. Your parents will also be asked to give permission for you to take part in this study. But even if your parents say "yes", you can still decide not to be in the study.

I will be grateful for your help.

If you decide you want to be in this study, please sign this letter. You and your parents will be given a copy of this letter to keep.

Yours faithfully,

---

Celeste Janse van Vuuren  
Researcher (Unisa student number: 35038837)  
Email: [celeste@childkinetics.com](mailto:celeste@childkinetics.com)  
Tel: 0829215236

## Agreement

I, \_\_\_\_\_, (your name and surname) have read this letter and I want to help Celeste Janse van Vuuren with her research study.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Celeste Janse van Vuuren

\_\_\_\_\_  
Date

## **Addendum F: Letter of Assent: Informed Assent (Afrikaans).**

### **BRIEF VAN INSTEMMING**

Datum:

Geagte \_\_\_\_\_

My naam is Celeste Janse van Vuuren. Ek is 'n student aan die Universiteit van Suid-Afrika. Ek doen 'n navorsingsprojek getiteld "Die impak van gestremdheid op die broers en susters van kinders met gestremdhede". Hierdie navorsingstudie hoop om te verstaan hoe die gestremdhede van 'n kind (jou broer of suster) 'n nie-gestremde broer of suster (jy) kan beïnvloed. 'n Navorsingstudie is 'n manier om meer oor mense te leer. Om deel te wees van hierdie studie sal jou die geleentheid gee om jou inligting te deel, wat gebruik mag word om die onderwerp beter te verstaan.

As jy besluit om deel te wees van hierdie navorsingstudie, mag jy gevra word om 'n onderhoud ("chat") saam met my te hê. Dit sal by die skool of by jou huis gebeur en op 'n tyd wat jou die beste pas. Die onderhoud gaan nie langer as 30 minute wees nie. Die onderhoud sal opgeneem word op oudioband vir my navorsingsdoeleindes. Ek het die opname nodig om die inligting te bestudeer nadat ons gesels het.

As jy wil, mag jy ook jou eie hoogtepunte of ander inligting met my deel. Daar is 'n "My eie hoogtepunte" bladsy opgestel, wat jy later kan invul, as dokumentasie wat my kan help met my navorsingstudie. Ek sal hierdie inligting wat gedeel word, met respek en vertroulikheid hanteer. 'n Tweede onderhoud ("chat") kan gereël word om die verdere inligting wat vir jou belangrik is te bespreek en / of as daar enige iets anders is wat jy wil deel oor hierdie onderwerp.

Jy hoef nie aan hierdie navorsingstudie deel te neem as jy nie wil nie. As jy besluit om te stop nadat ons begin het, kan ons stop en dit sal nie 'n probleem wees nie. Niemand sal kwaad wees as jy nie meer wil deelneem nie. Jy mag enige tyd vrae vra oor hierdie navorsingstudie. Ek voorsien nie enige risiko as jy besluit om deel te neem aan hierdie navorsingstudie nie. Jy hoef nie vrae te antwoord wat jou ongemaklik laat voel nie.

Wanneer ek klaar is met hierdie navorsingstudie, sal 'n verslag geskryf word oor wat geleer is tydens die navorsingstudie. Jou naam sal nie gebruik word op enige plek in die navorsingstudie nie. Jy sal nie enige geskenke of geld vir deelname aan hierdie navorsingstudie kry nie. Bespreek dit met jou ouers voordat jy besluit of om deel te wees van hierdie navorsingstudie. Jou ouers sal ook gevra word om toestemming te gee vir jou deelname aan hierdie navorsingstudie. Maar selfs al is jou ouers se antwoord "ja", kan jy nog steeds besluit om nie deel te neem nie.

Ek sal dankbaar wees vir jou hulp.

As jy besluit dat jy wel aan hierdie navorsingstudie wil deelneem, teken asseblief hierdie brief. Jy en jou ouers sal 'n afskrif van hierdie brief kry.

Die uwe,

\_\_\_\_\_  
Celeste Janse van Vuuren

Navorser (Unisa studentenommer: 35038837)

E-pos: [celeste@childkinetics.com](mailto:celeste@childkinetics.com)

Tel: 0829215236

### Ooreenkoms

Ek, \_\_\_\_\_, (jou naam en van) het hierdie brief gelees en ek wil Celeste Janse van Vuuren met haar navorsingstudie help.

\_\_\_\_\_  
Handtekening

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Handtekening van Celeste Janse van Vuuren

\_\_\_\_\_  
Datum

Addendum G: My Own Highlights Page (English).

# MY OWN HIGHLIGHTS



NAME:

---

Name your achievements or highlights – think of your school, sport, hobbies or special interests or any other activities.

---

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Have you ever been a leader? (for example class captain)

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Perhaps you have certificates, school reports, drawings, photos, poems, a diary or something else about yourself that you would like to share with me. If you can think of something, write it down here.

-

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I will appreciate it if you will be willing to share it with me. Even if you remember later about something which you haven't written down, I will still feel honoured if you share it with me.



**Addendum H: My Eie Hoogtepunte Bladsy (Afrikaans).**



# MY EIE HOOGTEPUNTE



**NAAM:**

---

**Noem jou hoogtepunte – dink aan jou skool, sport, spesiale belangstellings of enige ander aktiwiteite.**

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---

**Was jy al 'n leier? (Soos klasleier)**

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---

**Enige sertifikate, skool rapport, tekeninge, foto's, gedigte, 'n dagboek of enige iets anders oor jouself wat jy met my wil deel – Skryf dit hier neer:**

-

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Ek sal dit baie waardeer as jy bereid sal wees om hierdie inligting met my te deel.

Al onthou jy later van iets wat jy nie neergeskryf het nie, ek sal dit nogsteeds waardeer as jy dit met my deel.



## Addendum I: Interview Guide (English).

### Interview Schedule

<b>Name of research study:</b>	
<b>Time of interview:</b>	
<b>Date:</b>	
<b>Place:</b>	
<b>Interviewer:</b>	
<b>Interviewee:</b>	
<b>Duration of interview:</b>	

### Establishing rapport:

Describe the research project, tell interviewee of purpose of study, provide a structure of the interview. Explain the audio recording process, the reasons for taking notes, sources of data being collected and how long the interview will take. Ask if they have any questions, read and sign the assent form.

### Semi-structured interview

Possible questions to be asked with follow-up questions:	Researcher's notes	Reflective notes
<ul style="list-style-type: none"><li>• Tell me a little bit about yourself<ul style="list-style-type: none"><li>○ What are the things that you like to do?</li><li>○ When you grow up, what would you like to do or be?</li></ul></li></ul>		
<ul style="list-style-type: none"><li>• Tell me a little bit about your brother / sister<ul style="list-style-type: none"><li>○ What is he / she like?</li><li>○ What is it like to have XXX as a brother / sister?</li><li>○ Tell me about the good things and the not so good things</li></ul></li></ul>		
<ul style="list-style-type: none"><li>• Has anyone, like your mom / dad / someone else ever talked to you about your brother / sister's disability?<ul style="list-style-type: none"><li>○ If so, what did they say?</li><li>○ If not, would you like to know more about his / her disability?</li></ul></li></ul>		



<ul style="list-style-type: none"> <li>• Tell me a little bit about a time that was really difficult or challenging?</li> </ul>		
<ul style="list-style-type: none"> <li>• If you had Three Wishes, what would they be?</li> <li>○ Discuss each wish</li> </ul>	1. 2. 3.	
<ul style="list-style-type: none"> <li>• Do you think having a brother / sister with a disability is different from not having a brother / sister with a disability?</li> <li>○ If so, in what way?</li> </ul>		
<ul style="list-style-type: none"> <li>• Do you worry about your brother / sister?</li> <li>○ If so, what do you worry about?</li> </ul>		
<ul style="list-style-type: none"> <li>• Tell me about your responsibilities at home (your chores)</li> </ul>		
<ul style="list-style-type: none"> <li>• Do you have special 'alone time' with mom / dad?</li> <li>○ If so, what do you like to do?</li> <li>○ If not, would you like to have special 'alone time' with mom / dad and what would you like to do?</li> </ul>		
<ul style="list-style-type: none"> <li>• Does having XXX as a brother / sister limit what you can do?</li> <li>○ At home, at school, with friends</li> <li>○ If so, in what way?</li> </ul>		
<ul style="list-style-type: none"> <li>• Have you been teased / bullied because of your brother / sister?</li> <li>○ If so, how did you handle it?</li> </ul>		
<ul style="list-style-type: none"> <li>• Do you have friends who also have brothers / sisters with disabilities?</li> <li>○ If so, do you talk about it?</li> </ul>		
<ul style="list-style-type: none"> <li>• Do you like school?</li> <li>○ If so, what do you like about it?</li> <li>○ If not, what don't you like about it?</li> <li>○ What is your most favourite subject and your least favourite subject and why?</li> </ul>		
<ul style="list-style-type: none"> <li>• Have you ever talked to someone about</li> </ul>		

<p>what it is like to have a brother / sister with a disability?</p> <ul style="list-style-type: none"> <li>○ If so, how did it make you feel?</li> <li>○ If not, would you like to and why?</li> </ul>		
<ul style="list-style-type: none"> <li>• If you could change one thing in your life, what would it be?</li> <li>○ If so, explore</li> </ul>		
<ul style="list-style-type: none"> <li>• Is there anything else you want to tell me or ask me?</li> </ul>		

### **Closure**

Thank the interviewee for participation. Assure him or her of confidentiality of responses and confidentiality of use of documentation if provided.

## Addendum J: Onderhoudskedule (Afrikaans).

### Onderhoudskedule

<b>Naam van navorsingstudie:</b>	
<b>Tyd van onderhoud:</b>	
<b>Datum:</b>	
<b>Plek:</b>	
<b>Onderhoudvoerder:</b>	
<b>Persoon met wie onderhoud gevoer word:</b>	
<b>Tydperk van onderhoud:</b>	

### Inleiding:

Beskryf die navorsingsprojek, verduidelik die doel van die studie aan die deelnemer, verskaf en beskryf die onderhoud se struktuur aan die deelnemer. Verduidelik dat die onderhoud opgeneem sal word op oudio-kasset en die redes daarvoor. Verskaf die verwagte tyd wat dit gaan neem om die onderhoud te voer. Verskaf die redes vir die afneem van notas asook die gebruik en nut van inligting wat gevra word. Vra die persone of daar enige onduidelikhede is en of daar enige vrae is voordat daar met die onderhoud voortgegaan word. Lees deur en verduidelik die instemmingsbrief waarna dit ook geteken moet word deur al die nodige deelnemende partye.

### Semi-gestruktureerde onderhoud

Moontlike vrae wat gevra kan word en moontlike opvolg vrae:	Navorsers se notas	Nadenke / Refleksie- notas
<ul style="list-style-type: none"> <li>• Vertel my meer van jouself</li> <li>○ Wat is jou gunsteling dinge om te doen? (tydverdryf)</li> <li>○ Wat wil jy graag doen / wees wanneer jy groot is?</li> </ul>		
<ul style="list-style-type: none"> <li>• Vertel my meer van jou broer / suster</li> <li>○ Hoe voel dit om 'n broer / suster te hê wat 'n gestremdheid het?</li> <li>○ Vertel my van die goeie dinge en die nie sulke goeie dinge</li> </ul>		
<ul style="list-style-type: none"> <li>• Het enige iemand, soos jou ma / pa / iemand anders, al met jou gepraat oor jou broer / suster se gestremdheid?</li> <li>○ Indien wel, wat het hulle gesê?</li> <li>○ Indien nie, sal jy graag meer wil weet oor jou broer / suster se gestremdheid?</li> </ul>		
<ul style="list-style-type: none"> <li>• Vertel my 'n bietjie van 'n tyd wat baie moeilik was vir jou?</li> </ul>		
<ul style="list-style-type: none"> <li>• As jy Drie Wense het, wat sal dit wees?</li> <li>○ Bespreek elke wens</li> </ul>	1. 2. 3.	
<ul style="list-style-type: none"> <li>• Dink jy dit is anders om 'n broer / suster met 'n gestremdheid te hê as om nie te hê nie?</li> <li>○ Indien wel, op watter manier?</li> </ul>		
<ul style="list-style-type: none"> <li>• Is jy bekommerd oor jou broer / suster?</li> <li>○ Indien wel, waarom is jy bekommerd?</li> </ul>		

<ul style="list-style-type: none"> <li>• Vertel my van jou verantwoordelikhede by die huis (jou take)</li> </ul>		
<ul style="list-style-type: none"> <li>• Het jy tyd saam met mamma / pappa alleen?</li> <li>○ Indien wel, wat doen julle graag saam?</li> <li>○ Indien nie, sal jy graag tyd alleen wil hê en wat sal jy graag wil doen?</li> </ul>		
<ul style="list-style-type: none"> <li>• Is daar dinge wat jy nie kan doen nie, oor jou broer / suster 'n gestremdheid het?</li> <li>○ By die huis, by die skool en saam met jou vriende</li> <li>○ Indien wel, vertel my meer.</li> </ul>		
<ul style="list-style-type: none"> <li>• Was jy al geterg of geboelie deur ander oor jou broer / suster se gestremdheid?</li> <li>○ Indien wel, hoe het jy dit hanteer / wat het jy gedoen?</li> </ul>		
<ul style="list-style-type: none"> <li>• Het jy vriende wat ook broers / susters met gestremdhede het?</li> <li>○ Indien wel, praat julle daaroor?</li> </ul>		
<ul style="list-style-type: none"> <li>• Hou jy van skool?</li> <li>○ Indien wel, hoekom en waarvan hou jy?</li> <li>○ Indien nie, waarvan hou jy nie?</li> <li>○ Watter vak hou jy die meeste van en watter vak hou jy die minste van?</li> </ul>		
<ul style="list-style-type: none"> <li>• Het jy al met iemand gepraat oor hoe dit voel om 'n broer / suster te hê met 'n gestremdheid?</li> <li>○ Indien wel, hoe het dit jou laat voel?</li> <li>○ Indien nie, sal jy graag wil en hoekom?</li> </ul>		
<ul style="list-style-type: none"> <li>• As jy een ding in jou lewe kan verander, wat sal dit wees?</li> <li>○ Indien wel, eksploreer die antwoord</li> </ul>		
<ul style="list-style-type: none"> <li>• Is daar enige iets anders wat jy my wil vertel of vra?</li> </ul>		

### Afsluiting

Bedank die deelnemer vir sy of haar deelname aan die onderhoud en navorsingstudie. Verseker hom / haar oor die vertroulikheid en anonimiteit van die antwoorde en gebruik van dokumente indien hulle wel enige dokumente gedeel het.

## Addendum K: Observation Sheet.

### Observations Protocol (Field notes)

<b>Name of research study:</b>	
<b>Activity of observation:</b>	
<b>Date:</b>	
<b>Place:</b>	
<b>Time:</b>	
<b>Role of observer:</b>	
<b>Length of observation:</b>	

### Observations (Field notes)

Guideline	Observation notes	Reflective notes
<b>Environment:</b> Physical environment, Social environment, participants		
<b>Activities conducted:</b> Establishing rapport		
<b>Materials used during interview</b>		
<b>Interview</b>		
<b>Participant engagement</b>		
<b>Participant responses</b>		
<b>Relevant documentation if provided by participant</b>		
<b>Closure</b>		

## **Addendum L: Transcriptions (Four English Participants and One Afrikaans Participant).**

### **TRANSCRIPTIONS EMPIRICAL STUDY**

#### **PARTICIPANT 1**

##### **Interview: A**

Researcher: My name is Celeste. I am a student at the University of South Africa. I am doing a research study and this research study's name is "The impact of disability on siblings of children with disabilities". It hopes to understand how the disability of your brother or sister could impact you, the non-disabled sibling. And a research study is a way to learn more about people. Being part of this study will allow you to share how you feel and the information that you have that I could use to better understand the whole topic. If you decide that you want to be part of this you will be asked to have an interview. An interview is a chat at a time that suits you. The interview will be about 30 minutes, maybe shorter, but not longer. The interview will be recorded on audio tape; this is an audio tape (shows device) for me to listen to afterwards and for me to put all the information together. Then after the interview, you will be asked if you would fill in your own Highlights page at home. Then we can talk about it. That is the form of documentation that could help this study as well. I'll respect all the information that you share with me, now and the stuff that you give to me in the Highlights page. Everything will stay confidential. Confidential means private between you and me. In a follow-up interview we can discuss the extra stuff. You do not have to be part of this study if you do not want to. If you decide to stop after we start, that's ok too. No one will be mad at you if you do not want to be part of it. You can ask questions any time. And I don't see any risks, but if you feel uncomfortable about any question you can just ask to stop and then we stop. When I'm finished with this study I will write a report about what I've learned and this report will not have your name or where you come from in it. You will not get any gifts or money to be part of this study, it's all just voluntary. You can talk to your parents about this and if you don't want to be part of it. Your parents have been asked for their permission, but even if your parents say yes, you can still say no. I would be grateful for your help. Would you like to be part of it?

(The participant acknowledges that he/she agrees with instructions while it is being shared with him/her –nodding, eye contact, yes answers and openness to the discussion).

Participant 1: Yes.

Researcher: Ok. Then we are going to sign this letter to say that you are going to help me. You can use any colour pen; then I will copy it and give you a copy. It says – your name

and surname, today's date and your signature – if you have one. Then I will write mine there. (Indicates on paper where both parties should write and sign.)

Researcher: Ok. Tell me a little about yourself. The things you like to do.

Participant 1: I like to play cricket, I like playing with my friends. I like playing with my sister. I also like cycling in my estate and I like learning at school.

Researcher: That is good. And when you grow up what would you like to be or do?

Participant 1: I was liking to be a pilot, if I do not go that way I will also like to be a cricket or rugby player.

Researcher: A cricket player - what position?

Participant 1: I would take fielding, bowling, and batting.

Researcher: And Rugby?

Participant 1: In rugby, I will take a forward or forward area.

Researcher: Tell me a little about your sister.

Participant 1: She was born atTTTT hospital and after 11 days she was allowed to come home for the first time and she went through many difficulties with the hospital because she was in and out in and out. Eventually they put her on some sort of gas and as they took it off it damaged her brain.

Researcher: Who told you about these things?

Participant 1: My mom

Researcher: Ok,what is it like to have XXXX as a sister?

Participant 1: She likes playing a lot. She does get angry some times, she also hits a lot. We got a puppy on the SPECIFIC DATE GIVEN and she enjoys playing with CCCC.(the dog)She loves to be sporty and after one of her operations this year she wasn't able to run at all and we are looking for a school for her for next year. Because the school that she is in now has kicked her out for next year. Because she does not have any emotional sign of feelings. (Reflective note- very detailed descriptions and wording used by participant).

Researcher: Tell me about the good things about your sister?

Participant 1: She loves marshmallows. She loves my mom's spaghetti and bolognaise and also my mom's pizzas. And the lasagnes.She likes a lot of things.

Researcher: (Giggles and smiles while the participant gives the answers). She likes to eat...

Participant 1: She likes playing in the pool, she likes playing with her friends and sometimes when she is in the bath she will pretend that she is in the swimming pool and she just swims.

Researcher: How old is she?

Participant 1: On the SPECIFIC DATE GIVEN she will be 12.

Researcher: Ok, so that is her birthday.

Participant 1: Yes.

Researcher: And tell me about the not so good things.

Participant 1: The hitting; the punching; the kicking; the swearing; the screaming; the shouting...

Researcher: And how does that make you feel?

Participant 1: It sort of makes me feel depressed and hurt, especially in front of my friends, it makes me feel embarrassed. But that is the way she is going to be and also she doesn't really know how to climb trees and then she hurts herself. Like she will kick her foot against the pool accidentally, and when she was having the operation, she was willing to get up and walk all the time and the first night she came home, she was struggling to walk and she fell on the ground and she screamed.

Researcher: Has someone like your mom or dad or someone else talked to you about her disability?

Participant 1: My mother has a bit, but not too much in detail.

Researcher: Ok. And what did she say?

Participant 1: She said that she (NAME OF SISTER) was in and out the hospital quite a lot and the doctors put a needle in her when she almost did not have veins when she was young what caused her to swell up and umm that is all.

Researcher: Would you want to know more about her disability?

Participant 1: Yes.

Researcher: Tell me about a time that was difficult for you?

Participant 1: When, I think it was 2 years ago when she cut open her foot. She fell through the basin and it was quite hard not to temper her, because the stitches would pop. It was very hard for my family and for me.

Researcher: If you had any 3 wishes what would it be?

Participant 1: I wished that my sister was not brain damaged and I wish my friends would not be mean to me, sometimes. And my friends would not make fun of me.

Researcher: What about the first wish about the brain damage. Can we talk about that?

Participant 1: That she was able to walk better, to talk better, because her talking is not any good.

Researcher: And your friends not being mean to you? Tell me a little bit more about that.

Participant 1: That my friends will stop "dissing" me, it is like a thing they normally do.

Researcher: What is dissing?

Participant 1: Dissing is like when people make comments about you but they do not mean it.

Researcher: And when they make fun of you?

Participant 1: That they will stop making fun of me when I cannot do exercises properly, because I do not have upper body balance. And ja, that is all.

Researcher: Do you think having a sister with a disability is different from not having one?

Participant 1: No.

Researcher: Do you worry about your sister?



Participant 1: Yes, sometimes.

Researcher: What do you worry about?

Participant 1: I wonder why the school is so unreasonable that they could treat her for who she is.

Researcher: Ok. Tell me about your responsibilities or chores at home. Do you have any?

Participant 1: No.

Researcher: Ok. Do you have special alone time with mom and dad?

Participant 1: Umm, probably 5 minutes every single day.

Researcher: Ok, would you like more time?

Participant 1: Yes.

Researcher: And what would you like to do with mom?

Participant 1: I would like to go shopping with her even if I don't like it that much. (laughs a bit while saying this), just to make her happy and that my dad can stop going away so much that I can spend time with him.

Researcher: Does dad goes away for work?

Participant 1: Yes.

Researcher: And what would you like to do with dad if you can spend more time with him?

Participant 1: Play cricket, maybe play golf, and fly one of his aeroplanes.

Researcher: Yes, that sounds cool.(interest in expression on face and body).

Researcher: Does having XXXX as a sister limit what you can do?That means: not give you a lot of freedom.

Participant 1: It does give me a bit. But I do have to help in some instances.

Researcher: What instances do you have to help with?

Participant 1: Like sometimes I have to make her milk for school, I have to make her milk for now and ja.

Researcher: Ok and with your friends? Does it limit you what you can do with your friends?

Participant 1: Umm, NO, there is no limit.

Researcher: Have you been teased or bullied because of your sister?

Participant 1: (silence) YES.

Researcher: Ok and by whom?

Participant 1: By YYYY, he is in Grade QQQ.

Researcher: Ok how did you handle it?

Participant 1: I got frustrated and it felt like I want to hit him, but one of my friends' dads also got bullied, so he sorted it out.

Researcher: Do you have friends with brothers or sister with disabilities?

Participant 1: (Silence) I have a friend that has a cousin that has disabilities.

Researcher: And do you talk about the disability?

Participant 1: Yes because his cousin went to my sister's school.

Researcher: And do you feel it helps if you talk to someone that also knows someone with a disability?

Participant 1: Yes.

Researcher: In what way?

Participant 1: I feel more comfortable because he has the same feelings as I do and ja.

Researcher: Do you like school?

Participant 1: Ja, but I do not like DNT.

Researcher: What do you like?

Participant 1: I like that I get to learn new things every day and play with my friends and play cricket.

Researcher: What is your most favourite subject?

Participant 1: Afrikaans

Researcher: Your least favourite subject?

Participant 1: DNT (smiles)

Researcher: (giggles) Why?

Participant 1: Because umm, we do not get to do much in DNT. It is just a lot of explaining and that.

Researcher: Have you ever had the opportunity to talk to someone about how it is for you to have a sister with a disability?

Participant 1: Yes

Researcher: Who did you talk to?

Participant 1: I spoke to my friend ZZZZ

Researcher: And how did it make you feel to talk to someone?

Participant 1: It made me feel comfortable because I knew he had more or less the same problem with his cousin.

Researcher: If you could change one thing about your life what would it be?

Participant 1: I wouldn't change.

Researcher: You would not change anything?

Participant 1: Ja

Researcher: Is there anything else you want to tell me or ask me?

Participant 1: (Shakes head - no)

Researcher: Ok. There is your own highlights page that you could fill in. Then we can arrange a time and go through it. Thank you so much for this. Was it hard for you?

Participant 1: No, it was comfortable. (smiles)

### **Interview: B**

Researcher: Thank you for the effort you put into our previous session and for the effort for this second one. What did you bring with?

Participant 1: I brought a book of my sister and I and my parents. And (some silence), I just finished my, umm, Highlights page.

Researcher: Ok, what is in the book that you brought for me?

Participant 1: A photo book. (proud expression on face and body). It is 42 years old. (giggles)

Researcher: It is still beautiful and it contains a lot of memories. (impressed expression on face). It is a special part of you that you are willing to share.

Participant 1: It is 10 years from photos.

Researcher: (Wow) (Impressed and interested expression on face). What do you want to do first? The photos or the paper?

Participant 1: The paper.

Researcher: Your highlights paper. You said that the achievements that you have is cricket, rugby and school. Ok. Tell me about your highlights in cricket.

Participant 1: My highlights in cricket is getting my first wickets.

Researcher: Yes. (impressed expression on face and leaning forward in chair).

Participant 1: And working as a team.

Researcher: Cool. When did you get your first wicket?

Participant 1: I think it was the 000 of GGGGG. (date shared)

Researcher: (impressed expression on face).

Researcher: Wow that is special!

Participant 1: Yes.

Researcher: And how did the first wicket make you feel?

Participant 1: It made me feel happy, excited and happy.

Researcher: Ok and Rugby? Tell me about the highlights in rugby?

Participant 1: Watching rugby. S.A versus New Zealand with my dad and uncle and my uncle's friends. And unfortunately we lost. It was good fun seeing Joost Van Der Westhuizen.

Researcher: Where did you watch the rugby?

Participant 1: By soccer city. (Proud expression on face).

Researcher: And the soccer achievements or highlights?

Participant 1: Soccer achievements... I got over 324 goals yesterday. (giggles)

Researcher: Whoo-hoo!!!!, So you are a good soccer player? (smile on face)

Participant 1: Yes, but not as good as my friend RRRR.

Researcher: Ok. And your school achievements?

Participant 1: My school achievements are: Making new friends, playing, learning and having fun.

Researcher: Is making friends a difficult thing for you to do?

Participant 1: No. (shakes head no as well).

Researcher: You like making lots and lots of friends?

Participant 1: Yes.

Researcher: Ok, the next question was: Did you have any leadership. You said no. That is just fine.

Participant 1: Yes.

Researcher: Ok, and your school reports and certificates and things? You said: I'd love to share my school reports and photos of my sister.

Participant 1: Yes, but this one I couldn't bring today, because I was looking for it.

Researcher: It is fine, you can share it with me another time if you want to share it. What about your school reports do you like the most?

Participant 1: That the teachers always have nice comments to say and stuff like that.

Researcher: That is good, how does it make you feel to have so many things in your life and that you are so busy?

Participant 1: Happy.

Researcher: Ok. Let's go through the photos, if you want?

Participant 1: This is my mom and me... (pages through photo book and shows the pictures, naming what they did and where they went.

*A full discussion (in detail and spontaneous) took place while the researcher and the participant paged through the whole photo book. The participant enthusiastically and happily shared all the photos and details regarding the photos in the book.*

Researcher: This is so special. Thank you SO, SO, SO (emphasis on word) much for sharing this with me. I really appreciate it.

Participant 1: Yes, it is a pleasure.

Researcher: Thank you so much for being part of my research. And thank you for sharing all of this with me. How do you feel about sharing these very personal photos with me?

Participant 1: I feel comfortable.

## **PARTICIPANT 2**

### **Interview: A**

Researcher: Ek wil gou-gou net bietjie vir jou vertel / verduidelik van my studie of wat ek swot. Die studie gaan oor boeties of sussies wat 'n boetie of sussie het wat gestremdheid ervaar. Weet jy wat is gestremdheid?

Participant 2: (Participant nods head – affirmative in answer to question asked i.e. yes).

Researcher: Ok, kan jy vir my sê wat is 'n gestremdheid?

Participant 2: Ja dis 'n bietjie soos dom wees.

Researcher: Bietjie dom is,...ok. Ek studeer aan die Universiteit van Suid Afrika, dis UNISA. En ek hoop om met hierdie studie wat ek nou doen meer te verstaan oor hoe JY (emphasis on word in voice) voel en wat XXXX doen en wat sy ervaar, waardeur sy gaan en waardeur JY (emphasis on word in voice) gaan. As jy besluit om saam met my deel te wees hiervan, kan jy saam met my chat, by die skool of by jou huis. Ons

gaan so 30 minute besig wees. Ek neem dit op, op band, sodat ek by die huis daarna kan luister en kan opsommings maak. As jy wil, kan jy ook aan die einde die bladsytjie met “My eie Hoogtepunte” huis toe vat en saam met mamma en pappa invul of jy kan dit self doen – al JOU (emphasis on word in voice) hoogtepunte, sodat ek jou bietjie beter kan leer ken. As jy wil. En as ons mekaar weer sien, kan ons saam daardeur gaan. Jy hoef nie aan die studie deel te neem as jy nie wil nie. As jy besluit om te stop, kan ons stop, of as jy wil rus, of as jy nie verder wil praat nie, kan ons stop. Jy hoef nie te antwoord as jy nie wil praat nie. Ek dink nie daar is baie risiko’s om deel te neem aan die studie nie. Jy hoef nie vrae te antwoord wat jou ongemaklik laat voel nie. Jy kan net sê waarom jy gemaklik voel. Jy sal ook ‘n verslaggie of briefie kry oor al die resultate wat ek het. Jou naam sal nooit gebruik word nie. Ek gaan ‘n klompie ander kinders s’n ook kry en dit bymekaar sit en kyk wat se antwoorde kry ek. Dan gaan ek dit vir jou, mamma en pappa teruggee. Mamma en pappa het ook toestemming gegee. Gee jy toestemming? Wil jy deelneem? (The participant nods affirmatively). Ja? Dan gaan ons hier teken. Jy gaan hier so (the researcher points to the place on the assent letter where the participant should sign). Kan jy jou naam en van hier vir my skryf? Kan jy jou naam en van skryf?

Participant 2: Ja (the participant writes his details on the assent letter). (Silence)

Researcher: Hoe oud is jy?

Participant 2: Ses en ‘n half.

Researcher: Ses en ‘n half jaar? Vertel my bietjie meer van jouself. Wat is jou gunsteling dinge om te doen?

Participant 2: Ek hou daarvan om te speel.

Researcher: Ja, (with interest, the researcher leans forward). Watter speletjies?

Participant 2: Enige speletjie. (Sits and looks around, maybe thinking and maybe wondering, maybe looking around at surroundings).

Researcher: Gee vir my ‘n idee... (the researcher sees that the participant seems to find it challenging to think of games, thus the researcher provides a list of examples as a prompt for the participant to elaborate a bit more).

....Rekenaarspeletjies, binnespeel, buitespeel, self speel... (a bit of silence)

Participant 2: Binne en buite speel en met YYY speel.

Researcher: Met YYYYY speel?

Participant 2: YYYYY is groot. YYYYY kan vang en gooi en baie ander dinge doen.

Researcher: Speel julle baie saam?

Participant 2: Ja, het jy geweet ek speel nie baie met my ander sussie nie, Sy hou nie daarvan nie om te speel nie. Sy speel nie lekker nie.

Researcher: Hoekom?

Participant 2: Ek weet nie... (funny voice and a smile – shrugs shoulders).

Researcher: (Light laugh in reaction to participant's reaction).

Researcher: Ok, wat wil jy eendag doen wanneer jy groot is? Het jy al daaraan gedink?

Participant 2: Ek wil my eie kar kry.

Researcher: Jou eie kar? En watter kar is dit? (with a smile on face and in tone of voice).

Participant 2: 'n Merader (very proud and shows interest).

Researcher: Watse kar is dit? (with interest, the researcher leans forward)

Participant 2: Hy kan oor mure ry en oor twee karre op 'n slag. (uses hands as gestures to show and emphasis what has been said).

Researcher: (Shows interest in face and body). Sjoë, ek het nog nooit so 'n kar gesien nie.

Participant 2: Dis op Top Gear.

Researcher: Is dit op Top Gear? (shows interest and acknowledgement in face, tone of voice and body). Ek sal 'n bietjie Top Gear moet kyk. Ek maak hier 'n nota van Top Gear. (writes on page detail regarding conversation).

Participant 2: Ek dink dis op die internet ook.

Researcher: O, ok. Ek sal bietjie gaan Google. Ok, vertel my bietjie van XXXX. Hoe voel dit om XXXX se boetie te wees? Of om XXXX as 'n sussie te hê?

Participant 2: Dis nie so lekker om by haar te bly by die huis nie.

Researcher: Hoekom?

Participant 2: Want sy steel so baie geld. Sy het een keer R500.00 gesteel.

Researcher: Ja, waar?

Participant 2: My pa se wallet. (a more serious expression on face)

Researcher: Weet jy wat sy met die geld maak?

Participant 2: Uhm, nee. Al wat sy doen met die yster geld, is dit steel. En sy dink sy kan alles kry. (Silence).

Researcher: Vertel my die goeie goed van XXXX.

Participant 2: XXXX help baie mense.

Researcher: Hoe help sy baie mense?

Participant 2: Soos een keer het sy my gehelp om my koppie van die kombuis af te kry

Researcher: Hoe help sy nog ander mense?

Participant 2: XXXX help nooit my pa nie, heeltyd my ma.

Researcher: Hoe help sy heeltyd vir mamma?

Participant 2: Sy help in die kantoor en wil skoon maak. Elke keer, ewe skielik is die stofsuiers in die kantoor, wil net skoonmaak. (somewhat funny voice and researcher acknowledges it by smiling)

Researcher: Het enige iemand soos mamma, pappa of iemand anders al met jou gepraat oor XXXX se gestremdheid?

Participant 2: Ja.

Researcher: Wat het hulle gesê?

Participant 2: Hulle het gesê - dit is eintlik goed.

Researcher: Dat sy so is? (Voice a bit unsure – maybe unsure about answer / if participant understood.)

Participant 2: (Nods head – affirmative- to question asked)

Researcher: Vertel my bietjie meer daarvan.

Participant 2: Ja, sy kan baie by ouma en oupa wees. Sy het al klaar 2 keer saam met ons uit geeë. Dis nie baie keer nie.

Researcher: Hoekom sê jy dis nie baie keer nie?

Participant 2: Dis net een... twee... (shows on hand one and two fingers- counting)

Researcher: En waar is sy al die ander kere?

Participant 2: (Does not answer question, but continues with conversation). Sy was al 6 keer op my verjaarsdag.

Researcher: Ja, en wat doen hy/sy op jou verjaarsdag?

Participant 2: Sy sien net my maatjies. Sy sien NOOIT haar eie maatjies nie. (emphasis on word 'NOOIT' in voice).

Researcher: Hoekom nie?

Participant 2: Want dit is MY (emphasis on word expressed) verjaarsdag.

Researcher: En op haar verjaarsdag?

Participant 2: Sy sien nie een van haar maatjies nie.

Researcher: Vertel vir my bietjie van 'n tyd wat moeilik was vir jou.

Participant 2: Dis baie moeilik vir my as ek XXXX iets vra – om vir my water te kry.

Researcher: Hoekom?

Participant 2: Sy word "creepy" en dan kyk sy net vir my. Sy sê nie nee of ja. Sy is baie stupid. En sy sê huh?

Researcher: En dan, wat maak jy dan? (Silence)... Moet jy dan maar self die goedjies gaan haal?

Participant 2: Ja.

Researcher: Hou jy van die kyke wat sy vir jou gee?

Participant 2: Dit laat my baie 'creepy' voel.

Researcher: Sê my, as jy 3 wense het wat sou dit wees? Enige drie wense.

Participant 2: 'n Kar, my swembad en my duisend rand.

Researcher: Ok. Vertel my bietjie van jou eerste wens- jou kar-

Participant 2: 'n Merader.

Researcher: Dis die een wat jy op Top Gear gesien het?

Participant 2: Ja

Researcher: Ok. En hoekom is dit jou grootste wens?

Participant 2: Want hy kan deur mure gaan en hy kan oor 'n kar gaan.en hy kan oor 5 mense op 'n slag gaan.

Researcher: En jou swembad? Jou tweede wens.

Participant 2: Want ek soek 'n groot swembad en ek soek 'n Jacuzzi.

Researcher: Het julle nie 'n swembad by die huis nie?

Participant 2: Nee ons het nie. Ons moet nog steeds 'uitfigure' waar ons dit gaan sit.

Researcher: Praat mamma en pappa van 'n swembad?

Participant 2: Ja. Ons het al klaar n honderd keer daaroor gepraat.

Researcher: Kan jy swem?

Participant 2: Ja.

Researcher: Kan jy goed swem.

Participant 2: Ja, baie.

Researcher: Hou jy baie van swem?

Participant 2: Ja, baie. (shows eagerness on face and in body)  
(Shows 'impressed' expression on face). Ek het 5 medaljes.

Researcher: 5 net vir swem?

Participant 2: Ja (Shows impressed expression on face).

Researcher: En hoe laat dit jou voel?

Participant 2: Baie goed. (body language shows that he is very happy about his swimming- proud of himself). En ek het al 5 keer kompetisies gewen! (Proud expression).

Researcher: Sjoel! (shows interest in body and face). Dit is wonderlik! En jou R1000.00 wens.Waaroor gaan dit?

Participant 2: Want ek wil die hele 'tuck shop' koop. En ek wil my eie swembad koop.

Researcher: Dink jy dit is anders om 'n sussie te hê met 'n gestemdheid as om nie een te hê nie.

Participant 2: Dis eintlik lekker om haar te hê.

Researcher: Is dit lekker? (with interest in voice)

Participant 2: Ja, sy speel lekker BAIE met my. (emphasis on the word 'BAIE').

Researcher: Wat speel julle saam? Wat is julle gunsteling speletjies?

Participant 2: Bal vang en skoene gooi vir mekaar.

Researcher: Skoene gooi? (frown on face – body language asks for more elaboration).

Participant 2: Ja. Elke mens het een skoene, dan gooi mens die skoene- die een gaan daar (shoes with hands) en die een gaan hier (shows with hands).

Researcher: So, julle gooi hulle vir mekaar? (smile on face – sees the humor in the game).

Participant 2: Ja. Partykeer bump die skoene teen mekaar.

Researcher: Vertel my, is jy bietjie bekommerd oor jou sussie?

Participant 2: Nee. Nie so baie nie.

Researcher: As jy sê –nie so baie nie – is jy partykeer bekommerd oor haar?

Participant 2: Partykeer. As sy nie met my speel nie.



Researcher: Ok. Vertel my van jou take by die huis. Watter dinge moet jy doen?

Participant 2: Ek moet ALTYD (emphasis on word in voice) my eie water kry. Ek moet ALTYD (emphasis on word) my sussie se water kry. En ALTYD (emphasis on word in voice) my sussie se gunse doen. Ugh. Sy sê nie eens dankie nie. Ek moet altyd agter ZZZZ aanloop en haar water kry en sy sê nie eens dankie nie! Even moet ek haar naelpolish kry. (The participant mentions the other sibling in the family).

Researcher: En wat van XXXX?

Participant 2: Nee. Sy is te gestrem om dit te kry. Sy kou haar naels. Dit lyk nie mooi nie. Die EEN nael is heeltemal af. (shows with hand)

Researcher: En hoe laat dit jou voel as sy so haar naels kou?

Participant 2: Dit lyk so creepy-rig. Even my pa kou sy naels. Hy weet dit nie eens nie.

Researcher: Het jy tyd saam met mamma en pappa alleen?

Participant 2: Ja.

Researcher: Wat doen julle saam? Wat doen jy graag saam met pappa alleen?

Participant 2: Ek speel met hom sokker, krieket, even gooi bal met hom.

Researcher: Wat is jou tyd alleen saam met mamma?

Participant 2: Ek doen eintlik nie baie met haar nie. Ek het net een keer saam met haar sokker gespeel.

Researcher: En wil jy graag meer dinge saam met mamma doen?

Participant 2: Ja.

Researcher: Wat sal jy saam met mamma wil doen?

Participant 2: Ek sal (thinks a bit before answering) eintlik (thinks again before answering) baie bal saam met haar speel en krieket.

Researcher: En is daar dinge wat jy nie kan doen nie, oor jou sussie gestremd is.

Participant 2: Ek kan nie so lekker met haar bal gooi nie, want sy gooi nie so goed nie. Sy kan nie lekker bal gooi nie. Sy gooi net soos dit (shows and makes a noise – ugh.) Dan kom dit nie eens by my nie, dit kom nie eens in die lug nie.

Researcher: En by die skool?

Participant 2: Sy het 'n swembad by die skool.

Researcher: Is sy by haar eie skool?

Participant 2: Ja. Sy kan enige tyd swem wanneer sy wil.

Researcher: Was jy al geterg of geboelie deur ander kinders oor jou sussie se gestremdheid?

Participant 2: Ja, daai kind by die skool was lelik met my. (participant gives a small laugh). Sy was so 'creepy'.

Researcher: By jou skool, weet die kinders van jou sussie se gestremdheid?

Participant 2: Nee.

Researcher: Sal jy hulle eendag kan sê?

Participant 2: Nooit, want hulle gaan vir my lag. Hulle gaan dink dit is nie waar nie.

Researcher: En as jy maatjies oornooi? (Silence) Het jy al 'n maatjie oor genooi na jou huis toe?

Participant 2: Ok. Maar nee. Ek het al maatjies genooi wat in my ander skool is.

Researcher: En die nuwe skool?

Participant 2: Niks.

Researcher: Wil jy?

Participant 2: Ja.

Researcher: Was XXXX by die huis toe jou maatjies daar kom kuier het?

Participant 2: Ja.

Researcher: Hoe het jou maatjies oor haar gevoel?

Participant 2: Bietjie sleg.

Researcher: Hoekom?

Participant 2: Want my sussie is gestremd.

Researcher: Het jy vir hulle verduidelik, het jy vir hulle vertel?

Participant 2: Ja

Researcher: En, wat sê hulle?

Participant 2: Hulle sê sy is eintlik stupid. Hulle dink nie sy is nie gestrem nie. Hulle dink sy is stupid. Hulle weet nie wat gestremd is nie.

Researcher: Voel jy jy kan hulle vertel daaroor?

Participant 2: Ek voel ek kan, maar ek wil nie. Want dit voel nie lekker nie. Hulle sal vir my lag, want hulle weet nie wat gestrem is nie.

Researcher: Hou jy van skool?

Participant 2: Ja.

Researcher: Waarvan hou jy?

Participant 2: (Thinks a bit before answering) Toe ons die koekies gemaak het. Dis al.

Researcher: Hou jy van lees of wiskunder doen of daai goedjies...

Participant 2: Ek hou nie so baie van lees nie.

Researcher: En wat is jou gunsteling tyd by die skool?

Participant 2: Net toe ons die koekies gemaak het. Dit was lekker.

Researcher: Het jy al met iemand anderste gepraat oor hoe dit voel om 'n sussie te hê met 'n gestremdheid?

Participant 2: Ja. (nods head as well)

Researcher: Met wie het jy al gepraat?

Participant 2: Met van my maatjies by die skool. Die ander skool.

Researcher: En hoe het dit jou laat voel?

Participant 2: Bietjie funny.

Researcher: Het jy al met groot mense gepraat oor jou sussie se gestremdheid?

Participant 2: Net met een. Ek weet nie wat haar naam is nie, 'n juffrou.

Researcher: Ok. As jy een ding in jou lewe kan verander, wat sal dit wees?

Participant 2: Dat ek 'n swembad het, dat ek 'n Merader het en 'n R1000.

Researcher: Ok. Dis jou wense dan? (Participant nods head to affirm question asked). Enige iets anders?

Participant 2: Nee.

Researcher: Baie, baie dankie vir al jou antwoorde van al die vragies.

### **Interview: B**

No interview, according to the parent, the participant was not in the mood to attend another interview session. However, the participant filled in the requested document and the parent provided the researcher with the written document.

The following information has thus been documented as taken from the document collected:

Participant 2: The first question is about personal highlights that are special to the participant:

Dit word geskryf dat die participant 'n karate sensei in 'n game gewen het. Verder word genoem dat die participant trots is op sy eerste karate belt (geel) wat hy gekry het. Die laaste hoogtepunt wat hier gelys word is die helikoptervlug oor die Drakensberge waar die participant sneeu gesien het.

Die vraag oor leierskap: Die participant het genoem dat hy al twee keer klasleier was. Hy voel verder baie goed oor klaskleier wees en dat die kinders na hom luister.

Die derde vraag handel oor spesiale sertifikate of enige iets anders wat die participant as belangrik ag. Die participant het die volgende gelys: Hy het 'n spesiale sertifikaat vir karate gekry, 'n Goue sticker was gegee vir harde werk en hy het saam met die juffrou op die verhoog in die saal voor die ander kinders verskyn. Verder word gelys dat hy en die participant se ouer trots is op sy skool rapport. Laastens word bygevoeg dat die participant baie van sy nuwe "puppy" hou en ook van sy nuwe jagmes.

## **PARTICIPANT 3**

### **Interview: A**

Researcher: Good day, I am Celeste and I study at UNISA, the University of South Africa. I am doing a research study. The name is: "The impact of disability on siblings of children with disabilities". It is to understand how the disability of your brother or sister could impact you, the non-disabled sibling. And a research study is a way to learn more about people. Being part of this will allow you to share your information that you have that could be used to understand the topic better. If you want that you want to be part of this you will be asked to have an interview. An interview is a chat. The interview will be no longer than half an hour, that is 30 minutes, maybe shorter, but not longer. The interview will be recorded on audio tape; this is an audio tape (shows device) for me to listen to afterwards and for me to put all the information

together. Then after the interview, you will be asked if you want to fill in your own Highlightss page at home alone or with mom. Then we can talk about it. That is the form of documentation that could help this study as well. I'll respect all the information that you share with me, now and the stuff that you give to me in the Highlightss page. Everything will stay confidential. Confidential means private between you and me. In a follow-up interview we can discuss the extra stuff. You do not have to be part of this study if you do not want to. If you decide to stop after we start, that's ok too. No one will be mad at you if you do not want to be part of it. You can ask questions any time. And I don't see any risks, but if you feel uncomfortable about any question you can tell me and we will stop. When I'm finished with this study I will write a report about what I've learned and this report will not have your name or where you come from in it. You will not get any gifts or money to be part of this study, it's all just voluntary. You can talk to your parents about this and if you don't want to be part of it. Your parents have been asked for their permission, but even if your parents say yes, you can still say no. I would be grateful for your help. Would you like to be part of it?

(The participant acknowledges that he/she agrees with instructions while it is being shared with him/her –nodding, eye contact, yes answers and openness to the discussion).

Participant 3: Yes. I do want to.

Researcher: Ok. Then we are going to sign this letter to say that you are going to help me. You can use any colour pen; then I will copy it and give you a copy. It says – your name and surname, today's date and your signature – if you have one. Then I will write mine there. (Indicates on paper where both parties should write and sign.)

Ok, tell me a little bit about yourself?

Participant 3: Well, I am very neat and tidy. Sometimes on the weekends I mess up and so I have to clean it all up and I have a really happy life with my whole family. And my mom and dad love me lots. And I love them also.

Researcher: And what are the things you like to do?

Participant 3: I like to play with my toys. I pretend that they can talk. I cut my doll's hair, but it doesn't grow back, so I put in more hair. (smiles) I like to swim with my brothers. Sometimes we play tag in the pool.

Researcher: What is the tagging game?

Participant 3: We just play Marco, Polo and you are allowed to peek under water, because what happens when you bump into the wall and stuff.

Researcher: When you grow up - what would you like to be?

Participant 3: When I grow up I want to be a vet to help sick animals.

Researcher: Do you like animals?

Participant 3: I like horses and all kinds of animals.

Researcher: What is your favourite animal?

Participant 3: My favourite animal is a dog.

Researcher: Do you have dogs?

Participant 3: I have a Chihuahua and lots of different kinds of dogs.

Researcher: Ohoo! How many dogs do you have? (shows impressed look on face)

Participant 3: I have four dogs.

Researcher: Wow! (impressed)

Participant 3: We had three cats, but one ran away and one passed away. (some sadness on face shown)

Researcher: Oh dear. (empathy shown on face and voice). Ok. Tell me a little about your brother.

Participant 3: XXXX is left out most of the time because we think he is a little bit unpleasant to be with.

Researcher: Tell me more about why XXXX is unpleasant.

Participant 3: He sometimes swears at us, he calls us names; he is always sometimes mean to us. He tries to hurt us and then we tell our mother and then he says he did not do it. YYYY (the other brother, not disability) is like the same, he is a little bit rude. He sometimes is a little bit of mean. He sometimes hurts me. He does not like playing with me. (The participant has 2 siblings, one with a disability).

Researcher: How do you feel when they are rude to you or when they don't want to play with you?

Participant 3: It makes me unhappy because I like my two brothers. It is just that they are born different. I wish they could spend more time with me.

Researcher: If you say different, how you do mean different?

Participant 3: XXXX (brother with disability) is a little bit big for me. Sometimes he gets a little bit mean. And YYYY is also a little bit unpleasant for me. He also get a little bit angry when I try to do stuff with him.

Researcher: Has anyone like your mom or dad talk to you about the disabilities?

Participant 3: Yes, my ouma sometimes says when I want to say ugly things to him, I must just ignore it and then I just say nice things. Like, sometimes XXXX calls me a baby and then I will say ok XXXX, just please leave me alone. Then on my laptop, normally, I write nice things about my two brothers. And then sometimes I write bad things. So... (silence)

Researcher: Does it makes you feel better to write on you laptop?

Participant 3: Yes. (nods head as well). I will tell my parents about it, that it makes me feel angry, and then it makes me feel a little bit better.

Researcher: Did mom and dad tell you why XXXX is the way he/she is?

Participant 3: (nods head affirmatively – yes). XXXX was born yellow and he had a disability. The doctors in the hospital said he would not be able to walk or talk so we were just

afraid about that. He was the first born so. And then he actually did a lot of those things. He is doing very well in walking and very well in talking. When he was four or five or two, he started to talk. So they were quite surprised.

Researcher: And did mommy and daddy tell you all of this?

Participant 3: They told me this when I was 7.

Researcher: And how old are you now?

Participant 3: I am nine.

Researcher: Would you like to know more about XXXX's disability?

Participant 3: I am not sure because there is a lot of things about his disability.

Researcher: And YYYY?

Participant 3: He is just a little bit angry sometimes.

Researcher: Tell me about a time when that was difficult or challenging.

Participant 3: When I was about 4 XXXX started to be mean and push me around and YYYY did the same when YYYY started to grow up, he started to copy XXXX. And now we both copy XXXX because he is the older brother. So I just try and ignore it.

Researcher: If you had 3 wishes, what would it be?

Participant 3: That if my brothers ever had time to play with me. I will love that. My second wish will be if YYYY and XXXX will stop to be mean. My last wish will be that my brothers will love me more than they dislike me now.

Researcher: Your first wish was that your brothers should spend more time with you. Tell me a bit about that. What would you like to play?

Participant 3: I would love to play in the pool more times with them.

Researcher: And tell me a little about them being mean?

Participant 3: I am not really sure, but I would love if XXXX can stop calling us names and stop calling us ugly things.

Researcher: And if you say calling names and ugly things, like what would be said?

Participant 3: He calls us baby and other ugly things that I will not like to say.

Researcher: Ok and you say your third wish is for your brothers to love you more and not dislike you...

Participant 3: They don't like me because they sometimes say they wish I was not born.

Researcher: Both of them?

Participant 3: Yes, both of them.

Researcher: Do you think having a brother with a disability is different than having a brother without a disability?

Participant 3: I think that would work, but I love my brother the way he is.

Researcher: Do you worry about XXXX?

Participant 3: Sometimes.

Researcher: What do you worry about?

Participant 3: I sometimes worry about him when he climbs on the ladder and he is quite scared and moving the ladder. Then I will say XXXX if you are scared, you must climb down.

Researcher: What does he say?

Participant 3: He says OK, then thank you.

Researcher: Tell me about your duties at home, what do you have to do at home?

Participant 3: I have to clean my room. Sometimes I wash the dishes with my mom and I also help my brothers when they are doing the lawn.

Researcher: Do you have special alone time with mom and dad?

Participant 3: Sometimes. When YYYY goes to a friend and XXXX goes to the farm, I have time with my mom and dad.

Researcher: What do you like to do when you have alone time with mom and dad?

Participant 3: All I do is watch a nice movie with my mom and dad or if they are too busy, I will ask them to read with me.

Researcher: What is your favourite movie?

Participant 3: My favourite movie is The Lorax. It is a very nice movie.

Researcher: And when you read, what do you like to read?

Participant 3: I like to read my special book that my grandma gave me.

Researcher: Does having XXXX as a brother limit what you can do at home, at school or with your friends?

Participant 3: No. (silence). Sometimes with my friends, he will act like he is in love with my friends and then he will start calling us names. My friend doesn't like coming over to my house anymore and now I go to her house.

Researcher: Have you been teased or bullied because of your brother?

Participant 3: No

Researcher: Do you have friends that also have brothers with disabilities?

Participant 3: I am not really sure.

Researcher: Do you like school?

Participant 3: I love school. (big smile and proud expression on face).

Researcher: What do you like about school?

Participant 3: I love it when my friends at break time play with me and I get more friends. And I love school because we learn about new things.

Researcher: Do you like everything about school or is there something you don't like?

Participant 3: There is one thing I don't really like and that is when we have a test.

Researcher: Ok, what happens?

Participant 3: When they start giving the test words I get stressed.

Researcher: What do you do about the stress?

Participant 3: My teacher comes to me and ask me what is wrong. And then I say I think these words are a little hard for me and then she says just think that those words are very easy.

Researcher: And then?

Participant 3: Then I start trying the words.

Researcher: And then – (silence pause) can you do it?

Participant 3: Yes.

Researcher: That is good! (shows acknowledgement in expression). Have you ever talked to someone else about having a brother with a disability?

Participant 3: I think I talked about it with my friend QQQQ.

Researcher: And what did she say?

Participant 3: She says that she also doesn't really like XXXX. It makes me feel a bit unhappy because my brothers are very special to me.

Researcher: If you can change one thing in you life, what would it be? Is there something that you would like to change in your life?

Participant 3: Not really.

Researcher: Are you happy with everything?

Participant 3: Yes.

Researcher: Is there anything else you want to talk about or ask me?

Participant 3: No.

Researcher: Thank you so much for taking part in the interview. And everything will stay between you and me. Here is the highlights page if you want to do it, then we can talk about it in another session.

### **Interview: B**

Researcher: Good afternoon.

Participant 3: Good afternoon.

Researcher: Ok. Let's go through the highlights page. The first question was about any highlights that you want to share with me like sport or activities.

Participant 3: I wrote ballet.

Researcher: Yes, ballet medals and Spelling Bee and speech. How did those medals make you feel?

Participant 3: It makes me feel good because I have been doing ballet since the school started. I never want to quit.

Researcher: That is good! Ok, the next question is about the leader.

Participant 3: Yes. I have never been a leader. Sooner or late I will be one.

Researcher: Yes, that's right...sooner or later. You are very positive, that is very good.

Participant 3: I said that I draw and I knit. I went to a drawing competition and I won four medals.



Researcher: Wow! That is very good!

Participant 3: I drew a horse, the rest just drew the head but I drew the whole horse.

Researcher: Wow! That is very special and very good! Are you quite creative in that way?

Participant 3: Yes, (quite proud) I design with my mom, I made her shirt and a skirt and then I also read and colour.

Researcher: That is beautiful and special! You have a lot of things that you are very good in.

Participant 3: Yes, I put my drawings on my wall.

Researcher: That sounds beautiful! I appreciate it that you were willing to share these personal things with me.

## **PARTICIPANT 4**

### **Interview: A**

Researcher: Good afternoon.

Participant 4: Good afternoon.

Researcher: I am Celeste and I study at the University of South Africa (UNISA). I am doing a research study and the name of the research study is "The impact of disability on siblings of children with disabilities". It hopes to understand how the disabilities of a child (your brother/sister) could impact the non-disabled sibling (you). A research study is a way to learn more about people. Being part of this study will allow you to share the information that you have. It can be used in this study to better understand the topic. If you decide that you want to be part of this study, you will be asked to have an interview, this and after this. An interview is a chat. We are going to chat at school or home and at a time that suits you. The interview will be about 30 minutes, no longer than that. The interview will be recorded on audio tape (shows Dictaphone) so that I can go back and listen to it after our chat. You will also be asked to share your own highlights or any other extra information that you may have. You can do it afterwards, only if you want to. This documentation can also assist me in the research. I will respect all the information that you share with me and it will remain confidential. Confidential means just between you and me. The follow-up interview can be arranged to discuss the highlights page if you want to that. You do not have to be in the study if you do not want to. If you decide to stop after we begin, you can do that. No one will be mad at you if you decide that you do not want to be part of this study. You may ask any questions about this study at any time. I do not foresee any risks for you to take part in this study, if you feel uncomfortable about any questions; you can just tell me to stop, then you don't have to answer the question. When I am finished with this study I will write a report about what was learned and it will not include your name or state that you were in this study. You will not receive any gifts or money if you take part in this study. You can

discuss this with your parents if you want to be part or not be part of this study. Your parents have also been asked for their permission. Even if your parents say yes, you do not have to be part of this. Do you want to be part of the study?

Participant 4: Yes, I do.

Researcher: Ok. Then we are going to sign this letter. Your name and signature and mine as well. (Silence while the name writing and signing takes place). I will make a copy and you will get a copy of this letter.

Researcher: Ok. Tell me a little about yourself. What are the things that you like?

Participant 4: I like playing computer. I am also interested in the world so I like to go on the internet and do research and I also like playing outdoor sport and I also like doing swimming.

Researcher: When you grow up what would you like to do or be?

Participant 4: I think I would like to work with computers.

Researcher: OK. (shows interest in tone of voice and emphasis on word). Tell me a little bit about your brother?

Participant 4: My brother is really special to me. He is sometimes a bit annoying, but he always comes back. He helps me with a lot of things. He is a little clever, he thinks he can't read, but yet he can, because we let him go on the Gautrain every day and he knows when to stop and where to get on. And by the bus stop he also knows when to get off and when to get on. And also we swim together a lot. And ja, I really enjoy my brother.

Researcher: That is good, what is it like to have him as a brother? The good things.

Participant 4: Ok, my brother helps me a lot.

Researcher: What does he help you with?

Participant 4: Lifting stuff, playing with and sometimes he helps me with my homework.

Researcher: Homework? WOW! (impressed expression on face and in voice). And what are the not so good things about your brother?

Participant 4: Well, (some silence). He does call some people names, but he doesn't do it a lot. He can also be annoying.

Researcher: Annoying, tell me a little bit about that.

Participant 4: Like sometimes he will take pictures of us and put it on his iPod. Also like when I'm showering or something, he will just come in and take my clothes and run. It is really fun, (small giggle) but sometimes it is annoying.

Researcher: And what do you do when he takes your clothes and runs away?

Participant 4: Well, then I call my other sister and she will bring it back.

Researcher: Has anyone like your mother or father talk to you about your brother XXXX's disability?

Participant 4: Ja, they have spoken to me about it, but not much. Once when he went for a test, I think, and it said that he can't improve the way he is now. We were sad but we understand it now, we can help him still. We try.

Researcher: Ok and what did your mom and dad say? How did they explain it to you?

Participant 4: I can't remember what it is called, but they said that he has a problem with remembering things. They said that he can't read and write, but he can write some words, but he can't pronounce words right. He will read out the letters like "T- H -E" (says letters slow and phonetically).

Researcher: And do you help him?

Participant 4: Yes I help him.

Researcher: Tell me about a time that was challenging or really difficult for you.

Participant 4: I don't know if there was a time like that.

Researcher: Ok. If you had any 3 wishes, what would they be?

Participant 4: My first one would be to cure my brother's problem. Umm, the other ones...(some silence, thinking) I don't know...To have lots and lots of friends and another one would be to also ummm not go to school (giggles).

Researcher: Ok. So your first wish was to cure your brother's problem. Tell me a little bit about that wish. (Some silence). What would you want to do and what would you like to do?

Participant 4: He would probably be able to read more, so we can teach him from grade one all the way through again, so that he can understand better. And then he can get a proper job.

Researcher: Cool. And tell me more about your lots of friends wish?

Participant 4: I do have some friends, but other people don't like me for some reason, I don't know why. (some silence)

Researcher: Do they say to you why they don't like you?

Participant 4: They just don't talk to me. (smiles)

Researcher: Ok. Has it always been like that?

Participant 4: Ummm, yes. (shrugs shoulders)

Researcher: And your third wish was not to go to school...

Participant 4: Yes, (giggles) because I enjoy going to the farm. We work a lot and it is exciting for me.

Researcher: Do you think having a brother with a disability is different from not having a brother with a disability?

Participant 4: Well. I do think so. Because in the end it teaches you that you can look after your children when you are older, more better. And also probably you can help them a lot and then you don't fight a lot. Because usually children without that disability does fight a lot.

Researcher: Who fights a lot?

Participant 4: My other sister.

Researcher: With you?

Participant 4: Yes, like when I play computer and I just get up to get something to drink and then I see my other sister there playing already and then we start fighting.

Researcher: Do you also fight with XXXX

Participant 4: No.

Researcher: Do you worry about your brother with the disabilities?

Participant 4: Sometimes.

Researcher: What do you worry about?

Participant 4: Sometimes I worry that because he comes home with the bus, the bus will have an accident one day on the road. And also I am not much scared about everything, he knows not to go on the road, he knows a lot of things. We taught him all those things.

Researcher: That is good. Tell me about your responsibilities at home. Your chores that you have to do.

Participant 4: I usually on the weekends wash my dad's car. And to keep my brother busy I blow the leaves that fall, but now we have to put some compost down on the grass. We still haven't finished that yet. But my brother loves doing those kinds of things so I keep him busy doing it. But we don't get money and I don't mind.

Researcher: And on a daily basis? Are there things that you have to do every day?

Participant 4: I need to study. Basically that's all. And I need to revise the work that we did for the day.

Researcher: Do you have special alone time with your mom and dad?

Participant 4: No. Mostly my sister is with my mom and dad. And sometimes she is with my gran. And so then my mom and I get lots of time together. We like going to the shops together and my sister doesn't really like shopping, but I love going shopping with my mom. I don't get so much time with my dad.

Researcher: Which shops do you like to go to with mom?

Participant 4: First we usually go for breakfast at Mug & Bean and then we will go to the book store and look at the latest books to have, that came. Then we will go look at stuff for the kitchen and then we will go buy the food.

Researcher: Ooh. Ok. (shows impressed look on face and body) And with dad?

Participant 4: My dad usually works on the computer and he is like busy all the time. We don't usually...

Researcher: Would you like to spend more time with dad?

Participant 4: Yes.

Researcher: What would you like to do with dad?

Participant 4: Play games.

Researcher: What kind of games?

Participant 4: Sport outside, swimming and then games on the playstation like soccer.

Researcher: Ok. (impressed facial expression). Does having a brother with disabilities limit what you can do?

Participant 4: No.

Researcher: At school, at home or with friends?

Participant 4: No. I'm busy with what I like and I get my brother to play with me. And when my friends are there, he just stays in his room and he plays computer.

Researcher: Have you ever been teased or bullied because of your brother?

Participant 4: No. Never.

Researcher: Do your friends know that your brother has a disability?

Participant 4: Yes. And they understand. They actually kind of like my brother.

Researcher: Do you have friends with brothers and sisters with disabilities?

Participant 4: Not that I know of.

Researcher: Do you like school?

Participant 4: Yes. Sometimes. (smiles)

Researcher: Sometimes...(smiles and a small giggle)

Participant 4: Sometimes the work is fun and sometimes the work is boring.

Researcher: What do you like about school?

Participant 4: I like the sport and I like some of the school work, like a project, and I like spending time with my friends.

Researcher: What don't you like about school?

Participant 4: Sometimes the teacher and sometimes the work is hard and sometimes you have a fight with your friends.

Researcher: What is your most favourite subject?

Participant 4: Maths.

Researcher: What is your least favourite subject?

Participant 4: Umm...(giggle and laugh) Sepedi, I don't like doing it and D&T.

Researcher: Why do you like maths?

Participant 4: Most of the things are really easy to do. We have lots of fun in maths and we do a lot of stuff on the Smartboard.

Researcher: Why D&T?

Participant 4: We get homework on weekends.

Researcher: Oh No! Then you have to do homework the whole weekend...

Participant 4: (Participant nods head affirmatively and smiles).

Researcher: Have you ever talked to someone about your brother XXXX?

Participant 4: No, I don't know... Umm. Maybe, Ja. The psychologist.

Researcher: And how did that make you feel?

Participant 4: It made me feel a lot better because he said it is actually nice to have a disability brother because you can help him a lot and then you will know how to treat your children when you are older and he said he will play more than a non-disability brother would play.

Researcher: If you could change one thing in your life what would it be?

Participant 4: Umm (thinks a bit)(silence). Probably having my dad get another job, then we can play more.

Researcher: So you want dad to spend more time with you?

Participant 4: Yes. (nods head as well).

Researcher: Is there anything else that you would like to say or talk about.

Participant 4: No.

Researcher: Thank you so much for taking the time and for doing this. This is the highlights page that we can discuss in a follow-up interview and then we can talk about it if you want to.

Participant 4: Ok. Bye.

#### **Interview: B**

Researcher: Good afternoon.

Participant 4: Good afternoon, mam.

Researcher: Ok. Thank you for doing the highlights page. How did you feel about the highlights page that you did?

Participant 4: I felt good, but some of the things I did not have. I can't remember some of these things.

Researcher: The first thing you said was the achievements that you have in school, sport and hobbies. You mentioned achievements for poetry, expo. What type of poetry did you do?

Participant 4: We just had to pick a poem, then you had to say it to them and then you get different medals for how you did. Like browns, silver and gold. And a gold plus plus.

Researcher: And how did that make you feel?

Participant 4: Good

Researcher: That is special. And your expo?

Participant 4: I got a 80 percent to 90 percent.

Researcher: Wow! What kind of expo was it?

Participant 4: It was a science expo. Which soap works better to help prevent bacteria.

Researcher: Who worked on the expo with you?

Participant 4: Mmmm, a friend.

Researcher: Did mom and dad do something with you for it?

Participant 4: YES, (some excitement in voice). They did some research.

Researcher: And how was it to do something different with mom and dad?

Participant 4: It was nice. (Softer voice)- on a different level.

Researcher: And I see you say that you have not been a leader.

Participant 4: Yes.

Researcher: I see you got a diploma for poetry.And the gold plus. Now that you have talked to me about your highlights and what is going on at home with your brotherand the disabilities. How dus that make you feel?

Participant 4: I feel good, because I can help bring up my brother and it is nice to play with him a lot. And my other sister, but sometimes my other sister can be annoying.

Researcher: Do you feel that you have to be responsible for him? Do you feel you have to be there for himall the time?

Participant 4: No, he can do stuff on his own. Like taking the Gautrain and stuff like that.

Researcher: Thank you so much for sharing this with me and if there is anything you still want to share with me you can always come back and talk to me.

Participant 4: Bye.

## **PARTICIPANT 5**

### **Interview: A**

Researcher: How are you today?

Participant 5: Good thank you.

Researcher: My name is Celeste and I study at the University of South Africa (UNISA). I am doing a research study and the name of the research study is"The impact of disability of siblings of children with disabilities". It hopesto understand the disability of your brother or sister and the impack it may have on you. A research study is to learn more about the problem and how we can help people. And being part of this will helpus to understand how you feel and that can all be helpful for the research. Then if you decide that you want to be part of this study, we will have an interview. An interview like chatting to someone. The interview will be about 30 minutes. I will record the interview so that I can go back home and listen to it and put everything together. And at the end of the interview I am going to ask you if you want to share your highlights. Then you can take it home with you and you and mommy can go through it. Then we can go through it later in a follow-up interview and see what your highlights are. I will respect all the information and it will be confidential. Confidential means between you and me.I am not going to talk about it with anybody else.You do not have to be part of this study if you do not want to. If you want us to stop after we begin, because it gets uncomfortable, then it is also ok. I will understand and no-one will be mad about it or cross with you. You can ask

questions at anytime and I cannot see that there will be any risk for you if you take part. If you feel uncomfortable about any question, you do not have to answer it. You can tell me when you want me to stop. When I am finished with the study, I am going to write a report and give it to you as well. It will never have your name in it. You will not receive any gifts or money to take part in the research study. Your mom and dad will be asked for permission. Even if mom and dad say yes, you can still say no. Do you want to be part of this study?

Participant 5: Yes

Researcher: Ok. Then we are going to sign this letter. Your name and your signature. And mine.  
(Indicates on paper where both parties should write and sign.)

Researcher: Tell me a little bit about yourself.

Participant 5: I like to go on the jumping castle.

Researcher: Yes

Participant 5: I also like to play netball.

Researcher: Yes

Participant 5: And I like to ..... (Silence)

Researcher: Ok. When you grow up, what would you like to do or be? Have you thought about that?

Participant 5: A teacher and a lawyer.

Researcher: Ok and what are you going to do when you are a teacher.

Participant 5: I am going to be (silence)... teach Grade 5's.

Researcher: Ok and the lawyer? Do you know what a lawyer does?

Participant 5: Yes.

Researcher: Ok. Tell me a little bit about your brother? What is he like?

Participant 5: He sometimes he feels happy and sometimes he feels cross and sometimes he feels like hurting somebody.

Researcher: Ok. Tell me about the good things about him?

Participant 5: He likes to play games with me, especially teacher- teacher. He also likes to play hockey with my other brother. He also likes to play Wii (interactive computer game).

Researcher: Do you play with him on the Wii?

Participant 5: Yes.

Researcher: Tell me about the not so good things?

Participant 5: When he hurts me. That is all.

Researcher: Ok. Tell me about the hurting.

Participant 5: He sometimes smacks me.

Researcher: When does that happen?

Participant 5: If am watching a channel on TV and he wants to go to another channel and I change, then he will start hurting me.



Researcher: Ok and then what do you do?

Participant 5: I just call my mommy and she comes or my daddy. I have another brother and he says that I must try to ignore my XXXX (brother with disability's name). My mommy also says that I must ignore XXXX. My daddy says that I must just try and make XXXX happy.

Researcher: Ok. Would you like to know more about XXXX's disability?

Participant 5: Umm. (Silence) (Shakes head no)

Researcher: No?. Tell me about a time that was really challenging or difficult for you.

Participant 5: Mmmm (thinking). Like when he hurts me.

Researcher: If you had any 3 wishes, what would they be?

Participant 5: Umm. (thinking) One if I had a TV in my room.

Researcher: Yes.

Participant 5: Another one will be if XXXX can stop hurting me. The last one will be if I had my own make-up.

Researcher: Now tell me a little bit about the TV in your room. If you had this wish, what will you do about the TV in your room? What will you watch, what will you do?

Participant 5: Amm (thinking) when I am done bathing then I do not have to go downstairs. I can watch TV in my room.

Researcher: Ok and your favourite programmes?

Participant 5: (The participant gives the channel numbers and names of stories that the participant prefers to watch).

Researcher: Ok and your wish about your brother to stop hurting you. Why do you think you want to wish that?

Participant 5: Because when he hurts me, it feels sore.

Researcher: Ok and your own make-up? What will you do with your own make-up?

Participant 5: When I go to parties (thinking) and when I am going out.

Researcher: Cool. (shows impressed expression on face). Do you think having a brother with a disability is different than having a brother without a disability?

Participant 5: They are both different.

Researcher: In what way?

Participant 5: XXXX sometimes dresses himself and XXXX also sleeps in my mom's bed at night. Then the other brother (brother without disability) dresses himself and he does not sleep in my mom's bed.

Researcher: Do you worry about your brother with disabilities?

Participant 5: Ammm (thinking) Sometimes.

Researcher: What do you worry about?

Participant 5: We were reading a book last night and he struggles with some words.

Researcher: Ok and why do you worry about that?

Participant 5: Because I get all of the words right and he does not get all the words.

Researcher: And how does that make you feel?

Participant 5: Sad.

Researcher: Ok. Tell me about your responsibilities at home? What do you do at home?

Participant 5: Sometimes I wash the dishes. On Sundays and Saturdays I help my mom taking down the washing, while she is cleaning the kitchen... (Silence). Also sometimes, I clean the dining room table.

Researcher: And do you help XXXX with anything?

Participant 5: Sometimes.

Researcher: What do you help him with?

Participant 5: If there is a problem with his remote, I have to help him to control it.

Researcher: Do you have special alone time with mom and dad?

Participant 5: Umm (thinking)(silence) Not XXXX and YYYY? (mentioning the other siblings)

Researcher: Yes, not with them.

Participant 5: Umm (thinking)(Silence) NO!

Researcher: Would you like to?

Participant 5: Yes

Researcher: What would you like to do with mom and dad if you had special time with them? Let's do mom first.

Participant: With mommy, I would like to go shopping with her.

Researcher: Ok and dad?

Participant: With daddy, to go buy food and stuff with him.

Researcher: What kind of shopping with mom?

Participant 5: Woolworths, Edgars, and Mr Price.

Researcher: Are there things that XXXX does that limits what you can do at school or home or with friends?

Participant 5: No.

Researcher: Have you ever been teased or bullied because you have a brother with disabilities?

Participant 5: No.

Researcher: Do other children know that XXXX has a disability?

Participant 5: Only one of my friends.

Researcher: And what does he or she say?

Participant 5: She came to my house and then XXXX came in while we were dressing, then we screamed and my mom told XXXX to leave us alone.

Researcher: Do you have friends with brothers or sister with disabilities?

Participant 5: (Silence)(Thinking)(Shakes head no).

Researcher: Do you like school?

Participant 5: Yes.

Researcher: What do you like about school?

Participant 5: That we get to go to break and have lunch. (Both researcher and participant smiles).

Researcher: (smile) And what don't you like about school?

Participant 5: That we have lots of work.

Researcher: What is your most favourite thing of school?

Participant: Break. I also like spelling.

Researcher: Are you doing well in spelling?

Participant 5: Yes.

Researcher: What thing in class don't you like?

Participant 5: The one that I do not like is maths.

Researcher: Yes. Why not?

Participant 5: Because from the half of last year to this term I haven't gotten anything right in my book.

Researcher: And how does that make you feel?

Participant 5: Sad

Researcher: Have you ever talked to anyone about having a brother with disabilities?

Participant 5: No

Researcher: Would you like to talk to someone about having a brother with disabilities?

Participant 5: (Silence) No.

Researcher: If you could change one thing in your life, what would it be?

Participant 5: Umm (thinking) ...(Silence) NO!

Researcher: Is there anything else you want to tell me or ask me?

Participant 5: No.

Researcher: Ok. Here is a highlights paper. You can fill it in with mom, if you want to. Then we can talk about it in another interview. Thank you for all help.

Participant 5: Ok. Bye.

### **Interview: B**

Researcher: Good morning. And how are you doing this morning?

Participant 5: Good.

Researcher: Thank you for doing this highlights page for me. Did you have fun doing it?

Participant 5: Yes.

Researcher: And how do you feel about your achievements or highlights in your life?

Participant 5: I feel that it is good.

Researcher: Ok. Can we go through them?

Participant 5: Yes.

Researcher: You wrote down your achievements that you have for swimming. Are you still swimming for the A team?

Participant 5: Yes I am swimming tomorrow. A gala.

Researcher: Cool! Are you excited?

Participant 5: Yes! (proud and very happy)

Researcher: What is your favourite style of swimming?

Participant 5: Umm... What is it called? (Silence and thinks a bit). Breast stroke.

Researcher: Cool. And you are also saying here that you are learning how to play the piano.

Participant 5: Yes.

Researcher: Where are you learning how to play the piano?

Participant 5: I go to Miss ZZZZZ

Researcher: Ok. Do you enjoy playing the piano?

Participant 5: Yes. I like it!

Researcher: Do you have a piano at home that you can practice on?

Participant 5: Well... my mom says if I do well in grade 3, I may get a keyboard.

Researcher: A keyboard! That is cool. A keyboard is much more fun, it has more oomph and other sounds with it.

Participant 5: My cousin has one and she bought earphones. She says that you can put them in and then she can play and hear herself play.

Researcher: That sounds interesting. (smiles and acknowledges her achievements). You also say that you are doing well in gymnastics.

Participant 5: Yes, I do, but only on JJJJ (gives a specific day) days.

Researcher: Ok. And what parts of gymnastics do you like the most?

Participant 5: Umm. I like doing the splits and but now for our certificates and medals we have to learn all kinds of hard things.

Researcher: That is good and so special. The next question is about being a leader. I see you say yes for being a leader in Grade One.

Participant 5: Yes, because in grade two, the other classes do class captain but we do not.

Researcher: The next question is about reports or certificates or anything that you would like to share. I see you say that you and your mom could not find anything else. Only the Gold you got for your poem in Grade One and in Grade Two. Wow! Tell me about the poems.

Participant 5: Umm. Well I can't really remember them, but the one I had to read in front of all these people. And the other one I just read in front of my class.

Researcher: Cool!

Participant 5: The one was Afrikaans and the other one was English.

Researcher: Which one did you do in front of all the people? The one in Grade One or the one in Grade Two?

Participant 5: In Grade One

Researcher: Wow! Impressive. (shows impressed expression on face).

Participant 5: My friend says she had to do her one in front of 500 people last year. And she did so well.

Researcher: Sjoie! And you?

Participant 5: Yes. I did a Afrikaans poem and I got a A++

Researcher: That is very good. I really appreciate that you shared these personal things with me and it is good to say that you did these things for yourself. I think you have a lot of confidence.

Participant 5: Yes

Researcher: Ok. Thank you so much. I really appreciate that you were part of this study. Is there anything else that you want to share or want to say?

Participant 5: Uhm... No.

Researcher: Ok. Thanks.

Participant 5: Bye.

## **Addendum M: Document Sheet.**

### **Record of Documents as data**

<b>Name of research study:</b>	
<b>Date received:</b>	
<b>Place:</b>	
<b>Time:</b>	

### **Document examination summary**

<b>Type of document:</b>	
<b>Name of document:</b>	
<b>How was the document obtained:</b>	
<b>Summary of content</b>	
<b>Importance / relevance to study</b>	